

FINANCING HOME AND COMMUNITY-BASED LONG-TERM CARE:
ADULT CHILDREN CAREGIVER PERSPECTIVES

by

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ABSTRACT

Financing Home and Community-based Long-term Care:
Adult Children Caregiver Perspectives

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Large numbers of baby boomers and a shift towards home-based long-term care designate a need for a greater understanding of caregiver attitudes surrounding the financing of long-term home-based care. This study examined more fully the types of home-based long-term care services that family caregivers were utilizing for their parents. In addition, the willingness and ability of caregivers to privately fund these services for aging parents were explored.

The study utilized a preexisting data set of qualitative interviews that were conducted with 30 family caregivers helping to provide long-term care for an elderly parent or older-generation relative. Participants in the sample used many home- and community-based services such as home health aides and nurses, physical therapists, cleaning services and adult day centers. Often these services were funded via Medicare, Medicaid, care recipient funds, state programs, and caregiver funds. In addition,

caregivers were often willing, but unable to pay for long-term parent care on their own. Many caregivers in the study found paying for long-term parent care unnecessary. Family expectations, moral and religious responsibility, and a high aversion to nursing home care were cited as reasons for willingness to fund long-term care at home. Similarly, lack of family support and other personal obstacles were noted as reasons for inability to pay for care. Those who found payment for care unnecessary noted that care recipients had sufficient funds for their own long-term care.

(115 pages)

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CHAPTER I

INTRODUCTION

In the United States the current population of adults ages 65 and older is about 12% of the total population (U.S. Census Bureau, 2000). The number of older adults will continue to rise as advances in medicine increase life expectancy and large proportions of baby boomers reach retirement (Friedemann, Newmann, Seff, & Dunlop, 2004). As these adults age, they will need long-term care in varying degrees (Formiga, Ferrer, Perez-Castejon, Olmedo, & Pujol, 2007).

In the recent past some of this care has been provided via nursing homes and other types of institutionalized care (Stone, 2006). However, the current trend in elder care has moved away from nursing homes to community and home-based care (Bishop, 1999). In these settings, family members or friends are usually responsible for the care of elderly persons. Often, these family caregivers seek the aid of health or social service organizations in order to care for their loved ones in the home setting. This care is costly and finding funding to provide quality care can be discouraging if a caregiver does not know which avenues to take.

Statement of the Problem

While recent trends indicate a shift towards home- and community-based care (Bishop, 1999), it is important to identify what services home- and community-based care can provide for elders and their caregivers, as well as how this care is commonly financed. For family caregivers, home-based care services provide relief from the

responsibilities of long-term care (Kumamoto, Arai, & Zarit, 2006), and allow elderly adults to continue living independently for longer periods of time (Kassner, 2006a). These services often include nursing and medical services, homemaking and chore services, hygiene help, adult day services, and home delivered meals (Gollub & Weddle, 2004; Kassner; Pandya, 2004; Stone, 2000).

Although home- and community-based care can be less expensive than institutionalized care, caregivers still contribute an average of over \$5,000 out-of-pocket each year towards the costs of long-term care, which can create a large burden on caregiver families (Houser & Gibson, 2008). Elderly adults and their caregivers find themselves with limited options to pay for long-term care expenses. The most common options to pay for long-term care include Medicaid, Medicare, various state-funded programs, long-term care insurance, and paying for expenses with out-of-pocket monies.

Medicaid is a combined federal- and state-sponsored program that pays for long-term care for poor and low income individuals and individuals who become poor by spending down their assets and income while in long-term care (Feder, Komisar, & Niefeld, 2000; Ross & Wright, 1998; Stone, 2006). Medicaid is administered by states via joint state and federal government funding (Rice, Kasper, & Pezzin, 2009). Historically Medicaid has mostly paid for nursing home expenses, but in an effort to keep up with current trends and reduce its costs, efforts have been made to encourage home-based long-term care services by use of waivers to the program (Kaye, LaPlante, & Harrington, 2009; O'Shaughnessy, Lyke, & Storey, 2002; Palley, 2003; Stone). Today, Medicaid is the major source of government funding in most long-term care situations

(Rice et al.).

Medicare is a federally funded medical insurance program for almost all adults over age 65 and some disabled individuals (Feder et al., 2000; Rice et al., 2009). However, contrary to popular belief, Medicare only pays for medical costs when the medical services needed are of an acute nature (Stone, 2000). This means that Medicare typically only pays for long-term care services in select cases in which individuals are in short-term rehabilitation following an acute health episode (Feder et al.).

Other governmental assistance programs for caregivers vary from state to state. Many programs like the Alternatives Program of Utah or the state optioned Medicaid New Choices Waiver help families keep or take their loved ones out of nursing homes (personal communication, Michelle Benson, February 5, 2009). These programs often target those families who are just outside of eligibility requirements for Medicaid, but still struggle to pay for long-term care on their own. However, many of these state programs have long waiting lists and require a lot of paperwork in order to receive services. Additionally, these same programs are rarely expanded and will often be cut or limited in tough economic times (personal communication, Michelle Benson, February 5, 2009).

The number of people who have begun to rely on insurance to pay for long-term care needs is growing. However, only about 7% of long-term care is funded through a combination of long-term care insurance and private insurance (Feder et al., 2000). Additionally, long-term care insurance policies are costly and vary a great deal in what they cover (Beam & O'Hare, 2006). Thus, older adults may not know their options when

it comes to long-term care insurance and may not be able to afford decent coverage. Furthermore, some older adults may not use long-term care insurance due to the various reports of fraud and denied claims heard of from friends and in the news. These reports may cause many older adults to distrust the use of long-term care insurance (Waggoner, 2007).

Those who do not benefit from Medicaid, Medicare, private long-term care insurance or state-funded programs are usually left to foot the bill of long-term care themselves. Oftentimes, this is burdensome because long-term care is costly. This is exemplified in the costs of adult day services. In 2002, the average cost of adult day services was \$56 per day (Pandya, 2004). Because of such high costs, financing long-term care may take a toll on all involved. With limited options to pay for home care, and with each program having its own eligibility criteria, family caregivers may not know where to turn for help. In the past, little research has been done to explore the perspectives of family caregivers with respect to financing long-term care provided at home.

Theoretical Framework

To better understand the ways that family caregivers approach issues surrounding long-term care financing, an ecological framework is used to guide this study. Ecological theory assumes that individuals and families are shaped by, and in turn shape environmental influences and contexts (Chibucos & Leite, 2005). These environmental contexts are outlined in a model developed by Urie Bronfenbrenner and consist of multiple levels of interacting systems: micro-, meso-, exo-, and macrosystems (Bubolz &

Sontag, 1993; Chibucos & Leite; Sontag, 1996).

The ways that older adults and their family caregivers finance long-term care are influenced by each of these systems. The microsystem of long-term care may include familial attitudes towards long-term care and the commitment of family members to care for a parent in the home. The microsystem may also be influenced by the temperament of the elderly adult needing care or any children who are still living in the home.

Mesosystem elements of long-term care can include relationships of the family with home care providers or case managers helping caregivers obtain services. The next level of context, or the exosystem, can include the workplace and its caregiver friendly work policies (or lack thereof). Finally, the macrosystem of a family caregiver includes overarching environmental contexts like ever-changing long-term care policy and the eligibility of a care recipient to qualify for state and federal programs. The macrosystem can also include cultural contexts, as different cultures have distinct norms and feelings surrounding long-term parent care (Fitzgerald, Mullavey-O'Bryne, & Clemson, 2001).

Ecological theory also assumes that of these environmental contexts, some levels are much more influential than other levels on individuals (Chibucos & Leite, 2005). This means, for example, that a caregiver's commitment to providing care in the home for their elderly parent may have more of an influence on a caregiving situation than availability of funding for home care. This theory helps to more fully explain the motives and reasons for the caregiving decisions that family caregivers make than a theory that focuses on micro-interactions, such as social exchange theory.

Purpose of the Study

The purpose of this research is to increase understanding of the perspectives of family caregivers on the topic of financing long-term home-based care. This study utilizes qualitative analysis of data from in-depth interviews of family caregivers who are mostly primary caregivers to elderly parents or other close relatives receiving care at home. In the process of conducting this research, themes have been identified that help to more fully understand the experiences of family caregivers and the ways they pay for or expect to pay for long-term care of their relatives.

CHAPTER II

REVIEW OF LITERATURE

Overview

This chapter reviews the important issues surrounding the financing of home- and community-based care. First, long-term care and its settings, consumers, and types of services provided are briefly summarized. Next, home- and community-based care and its services are discussed. Finally, the characteristics of family caregivers and various methods for financing home- and community-based care as highlighted in the current literature are summarized. The chapter concludes with the research questions that are posed for this study.

Long-Term Care

Medical, social, or personal care that is provided over an extended period of time is generally referred to as long-term care (Ross & Wright, 1998). Typically, long-term care includes assorted supports and services, both formal (paid) and informal (unpaid), that focus on helping individuals maintain their independent lifestyles as long as possible when facing disability (Stone, 2006). As adults age, many will experience functional decline (Formiga et al., 2007), meaning that their level of ability to perform basic activities declines, leaving them less able to perform tasks necessary to remain independent. This requires a variety of help as time goes by, often beginning with minimal support (bill-paying and medication management) and leading up to the use of more supportive services (personal care and assistance with mobility).

Regardless of declining abilities, for many individuals, receipt of long-term care allows them to continue living in their communities and, in some cases, remain employed (Houser, 2007). Long-term care also helps to serve the social, environmental, and medical needs of disabled individuals (Stone, 2000). Long-term care has historically been low-tech in nature (i.e., helping individuals walk with the assistance of canes and walkers), but becomes steadily more complex as individuals with multiple medical needs are released from hospitals into traditional long-term care settings (Stone, 2000, 2006). Long-term care is discussed below. Individuals who receive long-term care, long-term care services, and long-term care settings are briefly highlighted.

Recipients of Long-Term Care

For people with disabilities of all ages, long-term care is important (Feder et al., 2000; Stone, 2000). Typically, long-term care recipients include individuals who are chronically or terminally ill, mentally ill, or physically impaired (Ross & Wright, 1998). Although adults of all ages may require assistance, older adults are the persons who are most likely to need long-term care services (Stone). Additionally, large numbers of people reaching very old age (75 years and over) will necessitate an increase in numbers of elderly adults requiring long-term care in the future (O'Shaughnessy et al., 2002; Ross & Wright; U.S. Census Bureau, 2008). As these older adults begin to need long-term care, they and those who care for them will face choices about where they will be cared for as well as what kinds of care they will need.

Long-Term Care Services

Long-term care can include several services (Palley, 2003; Spector, Cohen, &

Pesis-Katz, 2004; Stone, 2000). Some of these services address needs for assistance with activities of daily living (ADLs) such as: dressing, eating, grooming, toileting, ambulatory and mobility services, and bathing. Other long-term care services address instrumental activities of daily living (IADLs) or activities needed for independence, which can include: money management, medication management, transportation, and homemaker services (Feder et al., 2000; Ross & Wright, 1998; Stone). Medical and nursing services are also provided to recipients of long-term care (Spector et al.), and are provided by someone who is professionally trained in the health professions (Ross & Wright). Long-term care services can be provided in a variety of settings, as discussed below.

Long-Term Care Settings

The places in which senior adults reside can either enhance or impede their quality of life and independence (Stone, 2006). Voisine, Walke, and Jeffery (2009) assert that most elderly adults begin receiving long-term care in their own homes. As the health of these older adults begins to decline, their long-term care options start to decline as well, usually leading them to move to assisted living communities or nursing facilities as they become more frail and less independent.

Home-based long-term care, assisted living facilities, and nursing facilities are the most commonly cited long-term care settings. In most cases, decisions surrounding the long-term care of senior adults depend on the recipient's preferences and needs, costs and reimbursement available, and the availability of informal support from family and friends (Stone, 2000). This overview of long-term care settings will refer to Voisine et al. (2009)

outline and will discuss two of these long-term care settings. Home-based long-term care will not be addressed in this section, but will be discussed extensively later in this review.

Nursing facilities. Nursing homes are the major institutionalized setting for long-term care in the U.S. (Stone, 2000). Indeed, nursing homes are the chief long-term care providers for older adults with extensive disabilities (Bishop, 1999). In 2000, 4.5% of all adults ages 75 to 84 lived in nursing homes. In contrast, 18.2% of those 85 and older lived in nursing homes in 2000 (U.S. Census Bureau, 2005). This reflects the fact that nursing home placement for older adults increases with added longevity.

Elderly adults who reside in nursing homes typically require a range of medical, social, and personal services (Voisine et al., 2009). Additionally, many residents in nursing homes are unable to walk without help and most require assistance with personal grooming and dressing (Ross & Wright, 1998). Medical care is available for residents 24 hours a day (Voisine et al.), and nursing facilities allow for acute and continuous care to be provided as needed to residents. In many cases, nursing home residents are able to stay in the nursing facility for acute episodes of care, whereas in other long-term care settings they would be hospitalized (Kane & Kane, 2001).

In the majority of cases, nursing home residents have no family available or are not capable of providing long-term care for them (Ross & Wright, 1998). Furthermore most seniors prefer to receive services in their own homes for as long as possible (Gibson, 2003), with nursing homes being the least favored option for many elderly adults (Wright, 2004). Many family caregivers seek to honor these wishes, as well as their own, by caring for older adults in their home as long as they can before placing

them in a nursing home (Piercy, 1998; Piercy & Chapman, 2001). Generally, nursing home stays are paid for by Medicaid, private long-term care insurance, and out-of-pocket costs, while shorter stays related to acute care are paid for by Medicare (Feder et al., 2000; Kassner, 2006b).

Assisted living facilities. Assisted living facilities combine housing, health care services, homemaking services, and other personalized supportive services for residents (Voisine et al., 2009). Unlike many nursing homes, assisted living facilities aim to create a home-like atmosphere for residents, including private rooms and bathrooms (Stone, 2006). In addition to private apartment style units, assisted living typically provides some sort of group dining and access to personal care (Bishop, 1999; Stone, 2000).

Assisted living facilities began appearing in the United States during the 1980s (Wright, 2004). These facilities arose primarily in the private sector and rapidly became a popular long-term care alternative to nursing homes (Kane & Kane, 2001). Furthermore, by 2004 there were over 36,000 assisted living facilities that served around 938,000 residents, and at least 41 states provided some Medicaid coverage for assisted living facilities (Kassner, 2006a).

In the majority of cases, assisted living provides more custodial care than medical care, and residents are able to continue using previous health care providers.

Nevertheless, there are several types of assisted living facilities (Voisine et al., 2009).

Some facilities provide residents with high levels of medical services and have a full-time Registered Nurse on staff, while other facilities provide few medical services (Wright, 2004). Dissimilar to nursing homes, residents in assisted living facilities are more likely

to pay for care themselves or with private long-term care insurance because public subsidies for individuals using assisted living are limited (Wright, 2004).

Formal Home- and Community-Based Long-term Care

As elderly adults age, they increasingly begin to use and need extra services that are provided in the home and community (Calsyn & Winter, 2000). Because home- and community-based care is a form of long-term care, recipients of this type of care receive the same kinds of services that any recipient of long-term care would receive. More specifically, home- and community-based long-term care refers to assistance with daily activities that is required for people with functional limitations to remain in their home (Kassner, 2006a). Formal care providers arrive at a client's home between one and several times a week and provide relief for family caregivers, or carefully monitor and care for those who live alone (Kumamoto et al., 2006; Weissert, Chernew, & Hirth, 2003).

Home- and community-based care happens primarily in the home, but can also happen in some assisted living facilities, adult foster homes, or other supportive housing (Kassner, 2006a). Home- and community-based services are provided long-term and, in many cases, act as a substitute to permanent residence in a nursing facility for those older adults wanting to stay in their community setting (D'Souza, James, Szafara, & Fries, 2009). These services can include adult day services, medical home care services, chore and homemaker services, telephone assistance, home delivered meals, or a combination of the above. The next section briefly describes adult day services, medical home care services, chore and homemaker services, and home delivered meals.

Adult Day Services

Adult day services are a community-based group service that allows informal or family caregivers daytime relief from caregiving duties (Voisine et al., 2009). These daytime services are specialized to meet the needs of individuals with cognitive or functional disabilities and help these individuals to continue living at home (Pandya, 2004). Commonly, adult day programs provide nutritional, recreational, social, and health services to older adults during daytime hours (Dabelko & Zimmerman, 2008; Stone, 2006).

There are three main models of adult day services. These models are the medical model, the social model, and the specialized model (Stone, 2006; Voisine et al., 2009). Adult day services that follow the medical model offer intensive and therapeutic services in addition to social activities. Approximately 21% of all adult day services follow the medical model. In contrast, the social model of adult day services provides recreation, meals, and a few medical services. Thirty seven percent of all day services are based on the social model. Lastly, the specialized model focuses on specific population, for example, those with dementia. Nearly half of adult day centers are a combination of the medical and social models (Stone; Voisine et al.).

Pandya (2004) has asserted that adult day services are commonly paid for out-of-pocket by elderly adults and their families or via long-term care insurance policies. This is because public funding for such services are limited, although some centers do receive public revenue from state Medicaid home and community waiver programs or via the Older Americans Act, the Veteran's Administration, or the Social Services Block Grant.

In some cases, Medicare will also pay for adult day services if specific therapeutic requirements are met (Pandya).

Medical Home Care

Medical home care services are supplied through a range of providers (McGraw, Drennan, & Humphrey, 2008; Stone, 2000). These providers often include home health aides, nurses, and physical, speech, occupational, and respiratory therapists (Voisine et al., 2009). In recent years, home care has become more available to elderly adults and has become a viable alternative to nursing homes (Kane & Kane, 2001). This has created a shift from institutionalization, which was once the major option for senior adults with failing health, to home care where elders can be treated with services such as injections, catheterizations, monitoring of blood pressure, oxygen therapy, wound care, colostomy care, as well as other therapeutic services (Spector et al., 2004).

Kassner (2006a) states that in most cases, medical home care is paid for by Medicaid through individual home health care benefits in home- and community-based waiver programs. Kassner also indicates that in addition to Medicaid, Medicare also pays for some home health services when an individual is homebound, needs help periodically, and requires skilled nursing services. Out-of-pocket costs and private long-term care insurance also help to pay for the in home medical care of elderly adults.

Homemaker and Chore Services

In addition to medical care services, home- and community-based care are also characterized by homemaker and chore services (Spector et al., 2004). These supportive services can include yard work, property management, meal preparation, money

management, transportation and shopping for groceries; all of which contribute to the independence of elderly adults (Feder et al., 2000; Stone, 2000; Voisine et al., 2009).

Homemaker and chore services are typically paid for by out-of-pocket costs, but Medicaid does help pay for these services with an optional state Medicaid benefit, the personal care services program that provides assistance with daily living activities. In addition to this, the Older Americans Act also helps to pay for some in-home assistance with chores and homemaking (Kassner, 2006a). Furthermore, community and church organizations provide family caregivers with relief through various volunteer programs in which volunteers (often elderly adults themselves) help with various household tasks (Thompson & Wilson, 2001). One such program is Shepherd's Centers of America, a nationwide faith-based volunteer program for elderly adults wishing to help other elderly adults with their long-term care needs.

Home-Delivered Meals

Food and nutrition services are some of the basic services that are provided to many at risk populations, including older adults (Gollub & Weddle, 2004). As individuals age, they face specific dietary challenges (i.e., needing less calories, but still requiring the same nutrients). In addition, many older adults may also lack the income necessary to provide themselves with their daily dietary needs (Accius, 2008). Because of this, there are many programs designed to deliver meals to elderly adults in their homes. As this is done, elderly adults receive adequate nutrition (Accius). Adults who are not homebound may attend congregate dining at their local senior centers. The Older Americans Act provides funding for home-delivered meals for elderly adults over 60. In 2006,

congregate and home-delivered meals accounted for \$567 million of OAA funds (Kassner, 2006a). Home delivered meals may also be paid for with out-of-pocket monies of elderly adults and their families.

Family Caregiver Demographics and Responsibilities for Long-Term Care

As described above, in order for most elderly adults to continue living in their homes and communities, they need some form of caregiver support. Although paid caregivers provide much support to disabled elderly adults, it is the family and friends of senior adults who bear much of this caregiving responsibility (Ross & Wright, 1998; Stone, 2006). Undeniably, family caregivers are the “backbone” of the long-term care system in the United States (Coleman & Pandya, 2002; Houser & Gibson, 2008; Spillman & Black, 2005; Wolff & Kasper, 2006). Family caregivers typically fall into one of three categories by virtue of their relationship to the care recipients: adult children as caregivers, spouses as caregivers, and other family or friends as caregivers.

Adult children make up the majority of family caregivers, with adult children representing approximately 41.3% of all primary caregivers to elderly adults. Similarly, spouses make up another 38.4% of primary caregivers to elderly adults and other family and friends compose the last 20.4% of all primary caregivers (Wolff & Kasper, 2006). Because the majority of family caregivers are adult children, and because their finances typically are not pooled with those of their parents, this thesis is primarily concerned with the demographic of family caregivers that are the adult children or children-in-law of older individuals.

Like formal, or paid caregivers, family caregivers perform caregiving personal

care tasks, help with everyday tasks, and even complex health-related tasks (Houser & Gibson, 2008). While doing tasks such as helping with bathing, dressing, paying bills, or taking medications, family caregivers provide about 80 % of the caregiving needs for elderly family members. This means that paid care workers provide only about 20 % of caregiving services for older adults (Coleman & Pandya, 2002).

In 1998, the U.S. Department of Health and Human Services anticipated that family caregivers provided unpaid caregiving services in the amount of up to \$200 billion annually. Recently, Houser and Gibson (2008) estimated that these numbers had gone up, with about 34 million family caregivers providing approximately \$375 billion in unpaid caregiving contributions to senior adults in the United States. However, because family caregiving demographic data is limited, these numbers may actually be much higher than stated here (Houser & Gibson).

In addition to their unpaid services, family caregivers also contribute financially to the long-term care of elderly adults. While the majority (69%) of family caregivers experience little financial hardship as a result of care, caregivers providing large amounts of care (7%) do experience financial hardship (National Alliance for Caregiving, 2004). The National Alliance for Caregiving outlines five levels of caregiving demands. These levels begin at level one and steadily progress in caregiving intensity and responsibilities to level five. As levels of care increase, caregivers supply more and more financial support towards the care of elderly adults. In this study, level five caregivers spent approximately \$324 per month on caregiving.

Family caregivers also pay indirect costs as they provide support for older family

members. Adult children, more than spousal caregivers, cite lost family time, wages, and benefits as some of the indirect costs of family caregiving (Coleman & Pandya, 2002; Houser, 2007). Many of these family caregivers pass up job promotions, trainings, assignments, and job transfers or relocation because of their caregiving tasks (National Alliance for Caregiving, 2004).

These indirect costs can increase strain on families as caregivers struggle to pay for the costs of long-term care while meeting their own financial needs. In addition to being the children of elderly adults, most family caregivers are also women (Blieszner & Hamon, 1992; Mendez-Luck, Kennedy, & Wallace, 2008; National Alliance for Caregiving, 2004; O'Shaughnessy et al., 2002). Recent trends surrounding the postponement of childbearing and increased involvement in the workforce can create high stress caring situations where women are simultaneously trying to care for children and elderly parents while fulfilling employment expectations. These adult children are often termed as the "sandwich generation" because they are caught in the middle of providing care for their own children as well as their parents (Spillman & Pezzin, 2000).

With so many obligations pulling their attention and energy, in order to continue caring for elderly adults over a long period of time, adult children caregivers must either have strong ties to their parents, strong ties to caregiving, or both. While strong emotional ties to parents help explain continued caregiving in the face of obstacles, a strong commitment to caregiving, or a sense of filial responsibility may also help to explain why adult children continue to care for their aging parents over time. Filial responsibility is defined as a personal sense of obligation to care for and protect one's aging parents

(Blieszner & Hamon, 1992). Indeed, many adult children provide care and are willing to continue providing care because they are committed to caring for their aging parents over long periods of time (Piercy, 2007). Many caregivers turn to formal care services in order to respect their relatives' wishes to remain at home for as long as possible (Piercy & Dunkley, 2004).

Current Methods of Financing Long-Term Care

Although many adults will need long-term care as they age, few proactively plan for their own long-term care (Friedmann et al., 2004). This creates an enormous financial burden on elderly adults and their families as many of them struggle to pay for long-term care in their older years (Peters & Pinkston, 2002; Ross & Wright, 1998). The financial strain is exacerbated by the fact that family caregivers receive little public assistance in comparison to their many needs (O'Shaughnessy et al., 2002). Perhaps it is for this reason that some feel that the long-term care system in the United States is inadequate (Brody, Simon, & Smallwood, 1987; Peters & Pinkston). Regardless, there are four primary ways that long-term care is funded in the United States. These are Medicaid, Medicare, long-term care insurance, and personal resources (or out-of-pocket monies) (Ross & Wright; Spector et al., 2004).

Medicaid

In the United States, Medicaid is the largest source of financing for long-term care, especially nursing home care (Rice et al., 2009; Stone, 2000, 2006). Created in 1965, the Medicaid program is jointly funded through the federal and state governments,

administered through individual states, and designed to provide health care to the financially needy (Kaye et al., 2009; Ross & Wright, 1998; Stone, 2006). Inpatient and outpatient hospital services, nursing home costs, home health care, rural health clinic services, laboratory and x-ray services, and many others services are covered under Medicaid (Ross & Wright).

As a program designed for the poor, Medicaid's income eligibility requirements are quite stringent (Feder et al., 2000; Kassner, 2006b; O'Shaughnessy et al., 2002; Palley, 2003; Rice et al., 2009). While some older adults meet the criteria for Medicaid initially, many others become poor or "spend down" their resources because of the high medical costs associated with long-term care, thus qualifying for Medicaid after a period of time (Feder et al., 2000; Kassner; Peters & Pinkston, 2002; Temkin-Greener, Meiners, Petty, & Szydowski, 1993). Often, however, both individuals in a senior adult couple will not require long-term care at the same time. Because of this, the federal and many state governments have enacted laws that protect the spouses of elderly adults receiving long-term care from becoming impoverished by costs of their spouse's long-term care (Kassner; Ross & Wright, 1998).

During the 1960s and 1970s Medicaid primarily paid for long-term care services in institutionalized settings, but the 1980s marked new territory as Medicaid began offering home- and community-based waiver programs through various states to older adults (Kaye et al., 2009; O'Shaughnessy et al., 2002; Palley, 2003; Stone, 2006). In 2004, every state except Arizona had one or more home- and community-based Medicaid waiver programs (Kassner, 2006b). Waiver recipients must meet the same functional

criteria that they would need to meet if they wanted to receive care in a nursing home (Mollica, 2009). However, such waiver programs allow elderly adults receiving Medicare to stay in their homes and still receive the needed services that they would otherwise receive in a nursing home (D'Souza et al., 2009; Kassner; Kaye et al; Ross & Wright, 1998).

Supplementary programs like the personal care services program and home health care are additional benefits of Medicaid that states have the option of utilizing. These programs also allow seniors receiving long-term care to stay out of institutions and in their own homes and communities (Kassner, 2006b). By using waivers and programs like these, home- and community-based care may actually be saving the federal and state governments money over time. In fact, those states that have invested in home- and community-based care in recent years are experiencing slower Medicaid expenditure growth than those that have not invested in home- and community-based care (Mollica, 2009).

Medicare

Similar to Medicaid, Medicare was established in 1965. However, the primary goal of Medicare was not to provide health care to the poor, but to individuals 65 years and older (Feder et al., 2000; Moon, 2006; Rice et al., 2009). Unlike Medicaid, which is based on need, in order to receive Medicare benefits, elderly adults must have paid into the Social Security system via employment for 40 quarters or more. Older adults who do not have these work requirements have the option to purchase Medicare insurance on their own (Moon; Ross & Wright, 1998).

Medicare is not considered a chief financier of long-term care. Instead Medicare finances acute care, potentially including coverage for home- and community-based care for short periods of time (Stone, 2000). Although widely believed to finance long-term care, Medicare accounts for only 2% of all nursing home costs (Ross & Wright, 1998). This lack of understanding surrounding Medicare may contribute to poor planning for long-term care among elderly adults. However, recent increases in home health spending by Medicare are beginning to finance many more senior adults needing long-term care (Stone).

Even though Medicare does not finance most long-term care, it is able to finance long-term care through skilled nursing facility and home health benefits. Nevertheless, both of these benefits are still largely restricted to rehabilitative care after acute hospital stays (Feder et al., 2000; Stone, 2000). Home care benefits are covered under Medicare in two parts: Part A and Part B (Moon, 2006; Ross & Wright, 1998).

Part A of Medicare helps to pay for four types of basic medical care: inpatient hospital care, inpatient care in a skilled nursing facility after a hospital stay, hospice care, and home health care. The core reason that Medicare is not considered to fund long-term care is because each of these types of care is associated with a time limit for which Medicare will fund them (Ross & Wright, 1998). In most cases, Medicare will cover care in a nursing facility or at home for 100 days following a three day stay at a hospital (Feder et al., 2000). Part B of Medicare is an additional optional service available to any individual who qualifies for Medicare Part A. This option helps to pay for additional services not covered under Part A, for a monthly premium (Ross & Wright), however

these services are also not designed to include coverage of long-term care needs.

Long-Term Care Insurance

Due to the fact that Medicaid serves only low-income individuals and Medicare does not cover most long-term care needs, some elderly adults opt to purchase private long-term care insurance to help offset their long-term care costs (Ross & Wright, 1998; Stone, 2000). While long-term care insurance can be purchased individually, employers are increasingly making long-term care insurance available through benefits packages where employees may purchase coverage. In some cases, employers may pay some or all of the premiums for their employees and retirees (Beam & O'Hare, 2006).

Beam and O'Hare (2006) indicated that when purchasing long-term care insurance, individuals are faced with a plethora of options. This variety is related to the many types of long-term care available. Typically, these variations fall under three types of policy categories. These include facility-only policies, home health care policies, and comprehensive policies. Facility-only policies are those that cover only nursing home, assisted living, or hospice care. Home health care policies are designed to provide benefits for care outside of an institutional setting and, in some cases, assisted living facilities. In contrast to facility-only policies and home health care policies, Beam and O'Hare noted that comprehensive policies cover both institutional and at home settings.

Regardless of these options, there are few seniors who actually purchase long-term care insurance, and private long-term care insurance covers only a fraction of overall long-term care costs (Feder et al., 2000; Kassner, 2007; Peters & Pinkston, 2002; Ross & Wright, 1998; Stone, 2006). This may be because many older adults may not trust

long-term care insurance because of problems associated with claims denial and fraud (Waggoner, 2007). However, it is more likely that private long-term care insurance is not affordable to many older adults (Kassner; Peters & Pinkston).

Age is also factor for many older adults purchasing long-term care insurance policies. Those who choose to purchase long-term care insurance earlier in life will pay lower premiums than those who wait until later in life to purchase a long-term care policy (Beam & O'Hare, 2006). Thus, many older adults may find that purchasing long-term care insurance as they need it is not a financially viable option.

It is obvious that private long-term care insurance does not provide much relief from the costs of long-term care. Regardless, the federal government has made efforts to encourage individuals to purchase private long-term care insurance. The primary method by which this has happened is through tax relief. Most policies sold today meet the federal standards for tax deductions (Kassner, 2007; O'Shaughnessy et al., 2002), although few taxpayers pay enough in medical costs to be able to itemize these deductions under current social policy (Kassner).

Personal Resources and Out of Pocket Costs

As discussed above, many older Americans and their families face and are surprised by the enormous out-of-pocket costs for long-term care (Peters & Pinkston, 2002; Stewart, 2004). This may be because they assume that Medicare or Medicaid will help to cover these costs. More than one quarter of all long-term care costs are paid directly by elderly adults and their families. In addition, family caregivers often give up their time and many opportunities to care for aging family members (Feder et al., 2000).

These costs can create a large burden in the lives of elderly adults and their caregivers (Peters & Pinkston).

Summary

Financing long-term care will become more and more important as an entire generation of baby-boomers moves into retirement and old age. While long-term care can be provided in a variety of settings, elderly adults commonly prefer to stay in their own communities and homes to receive long-term care services. Consequently, home- and community-based long-term care has evolved and now offers many services to those who prefer their own homes over institutionalization. But how these services will be paid for in the future is less clear.

In the past, elderly adults and their caregivers have paid for home- and community-based long-term care in a variety of ways. Most commonly this care has been paid for via Medicaid, Medicare, private long-term care insurance, and out-of-pocket resources. While much is known about the general trends in home- and community-based long-term care, less is known about the realities that face senior adults and their family caregivers in regards to financing long-term care.

This research is timely because the number of older adults who will need home care services is likely to increase, while publicly-supported services like Medicare, Medicaid, and state programs may not increase to meet this demand. Thus, not only will family caregivers be called upon to provide more care for long periods of time, but they may also be faced with helping to pay for care that is otherwise inaccessible. This study seeks to understand the experiences that elderly adults and their family caregivers have

while navigating the home- and community-based long-term care system.

Research Questions

The purpose of the current study is to gain greater insight to what long-term care services are utilized by elderly adults, how these services are financed, caregiver's abilities to pay for these options, and the reasons these caregivers choose to pay or not pay for long-term care in the home. The questions that guide this research are as follows:

1. What are the home- and community-based services that are used by the family caregivers of elderly adults? In what ways are these services being financed?
2. To what extent are family caregivers willing or able to pay for long-term parent care in the home?
3. What are the reasons that families pay or choose not to pay for long-term parent care in the home?

CHAPTER III

METHODOLOGY

This study delves into the experiences of family caregivers to elderly adults while they are navigating the long-term care system. Research questions for this study center on the types of home- and community-based services that family caregivers and elderly adults utilize and how they pay for these services. Moreover, the ability and willingness of family caregivers to pay for long-term care in the home, and the reasons they choose or choose not to pay for care in the home are addressed. A qualitative approach, with a cross-sectional in-depth interview design was used for this study, as it helped to understand more fully the experiences of the purposeful sample of caregivers in the study. This chapter will discuss the sample, data collection, analysis, and reporting of the study.

Sample

This study utilizes the interviews of 30 participants from a pre-existing data set. Of those 30 participants, 29 were female and 1 was male. Twenty-one of the participants were the daughters or son of the older adult care recipient. Eight participants were daughters-in-law or stepdaughters and one participant was the niece-in-law of the care recipient. Nearly one-third of the participant caregivers were the oldest sibling in their family, or an only child. Ages for participants in the study ranged from 39-67 with a mean of 51.2 years of age ($SD = 7.2$ years).

For caregivers in the sample, the mean number of years of education was 13.08

($SD = 2.8$). Seventeen of the participants indicated that they worked outside of the home. Those working outside of the home worked a range of 8 to 80 hours per week, with 12 of all participants in the study working 40 or more hours per week. Two participants were retired.

The majority of participants in the study indicated that their financial resources were adequate or more than adequate (63.3%), while 33.4% of the participants fell below that, feeling that their financial resources were less than adequate, and 3.3% of the participants felt that their financial resources were more than adequate. Only 21 participants reported a family income. Of those that did, 38.1% made less than \$30,000 and 61.9% made more than \$30,000, with 38.1% of those making an annual income of \$50,000 or more.

Marital status of participants indicated that 83.9% were married, 9.7% were divorced, and 6.5% were single and had never been married. Similarly, the mean number of children living in the caregiver's home was 1.6 ($SD = 1.9$). All of the participants indicated a religious preference. Twenty nine or 93.5% of the participants were members of The Church of Jesus Christ of Latter-day Saints (LDS), one participant was a member of the Catholic Church, and one participant indicated being Christian. Thirty of the 31 participants indicated that religion was very important to them.

The elderly adult care recipients of the participants in this study ranged in age from 67 years to 100 years with a mean of 83 years ($SD = 7.2$). Participants in the study typically gave care to women (61.3%), but those caring for men made up 19.4% of the sample, and some caregivers were providing care to both male and female care recipients

(19.4%). Caregivers in this study had been giving care to an elderly adult between three months and 13 years. The mean for number of years providing care was 3.5 years ($SD = 3$).

Of the thirty-one participants in this study, 9 (29%) indicated that the older adult they were caring for was receiving some form of Medicaid. Additionally, 17 (54.8%) of participants noted the use of Medicare for the elderly adult they were caring for, and 4 (12.9%) were using state funds to help pay for long-term care. Only 10 (33.3%) of the participants indicated that they were not using any personal funds at all, while the rest of the participants were either using their own funds, care-recipient funds, or a combination of the two to pay for care. Similarly, only 2 (6.5%) of the participants were using insurance to help pay for long-term care.

Procedures

At the outset, this study was approved by Utah State University's Institutional Review Board (see Appendix A). Several methods were used to recruit participants for this study. Home Health Agencies, a Senior Citizen Center, and four county Area Agencies on Aging were contacted and asked to provide names, or nominate possible caregiver families. In addition, students taking Family and Human Development classes at Utah State University were asked to recommend their own families if they were providing care for an older adult who was using at least one service. An announcement about the study was put into the newsletter of the Cache County Study of Memory, Health, and Aging, which was being conducted concurrently at Utah State University.

Upon nomination, families were contacted by phone and screened for eligibility

before interviews were scheduled. In order to qualify to be in the study, families had to be providing care for a minimum of three months to an older family member who needed help with one or more activities of daily living or instrumental activities of daily living. The older adult receiving care had to be using or had recently used one or more of the following services: speech, physical or occupational therapy, adult day services, skilled nursing care, mental health, respite care, hospice care, or senior center activities.

Prior to beginning the interviews, two focus groups were conducted. One was carried out with family caregivers and the other was conducted with health care providers. The purpose of these groups was to explore issues that would help to shape and refine interview questions. The focus groups were able to identify important issues surrounding caregiving, like family issues, the use of formal care systems, and the influence of government policy on service provision.

After the focus groups were conducted and interview questions refined, nominated family caregivers were contacted and interviewed. Caregivers in the study were paid \$20.00 as compensation for their time. Interviews were carried out by the principle investigator who is a professor at Utah State University, three graduate level research assistants, and one undergraduate research assistant. Before the first interview, each participant was given a consent form which explained the purpose of the study. The consent form also indicated that participation was voluntary and their names and the names of care recipients would be kept confidential. Upon reading and signing the consent form, interviews were conducted. Two separate interviews were conducted with each participant, at a week to two weeks apart unless participants indicated they would

like to receive both sets of interview questions at once. If this happened, the participant's wishes were honored, and both sets of interview questions were administered. Interviews lasted from 45 minutes to 2 hours. After the interviews were conducted, they were transcribed verbatim. Participants were also asked to fill out a demographic questionnaire. The questionnaire asked questions about caregivers and their care recipients.

Instruments

During the semi-structured interviews, participants were asked a series of questions designed to elicit various open-ended responses. During the first interview, general caregiving and home-care questions were asked to help uncover the perceptions and facts of caregiving in the lives of participants. General caregiving questions set the stage for the interview by asking about the caregiving situation, what brought the participant to the caregiving role, if any other family members help to provide care for the care recipient, and what agencies and services participants and their care recipients used. Likewise, home care questions asked about home care specifically. These included questions such as: "What kinds of help does home care provide?", "Who is paying for this episode of home care?", and "How satisfied are you with the services provided by the home care agency or person?"

In the second interview or, for some, immediately after the first set of interview questions, participants were asked the second set of interview questions. General topics for the second interview include economic and other issues, choices for long-term care, and financing long-term parent care at home. Economic and other issues questions asked

about some of the financial consequences of providing care for an elderly parent.

Similarly, choices for long-term care questions asked questions like: “Other than the services of the home care agency you are receiving now, what choices for outside help do you have?”, “Are you aware of other home care or community programs for which your parent may qualify? What are they?”, and “If you wished to continue home care, but the regulations of the program you were using stipulated that your parent was no longer eligible for services, what would you do?” The section that addressed the financing of long-term parent care at home contained the most questions. Participants were asked if their parents were able to pay for their own care, if they would be willing to pay for the care of their parent, and if there was anyone else participants could ask for financial assistance with home-based parent care. Reasons for helping or not helping parents with care payment were also explored. The full interview protocol is in Appendix B.

As discussed above, participants were also given a questionnaire at the end of the interviews. This questionnaire was primarily to obtain demographic data from the participants. This questionnaire asked questions about participant’s families—including how many siblings and children they had, religious preference, years of education, and income. Questions also asked about the care recipient’s age, gender, resources, and what types of funding were used to pay for long-term care. The complete questionnaire is contained in Appendix C.

Role of the Researcher

Because of the qualitative nature of this study, it is important to be aware of

researcher subjectivity (Peshkin, 1988). Because of this, I have tried to recognize my subjectivity and biases as I analyzed the data for this study. I am not a family caregiver. I have never experienced the long nights and stressful days that come with caring for an older adult, and wondering how to pay for that care. However, I have watched as my parents cared for my own grandmother. They did this in addition to raising eight children. Although young at the time, I know, albeit second hand, what a challenge it was for them as they cared for her and struggled to pay for that care. What they experienced, I may never fully understand. However, this study has opened my eyes to their experience and the experiences of the caregivers in this study, even if just a small fraction of them.

In addition to a daughter, granddaughter, and bystander, I am also a researcher who is interested in the challenges that face family caregivers. As a researcher, I hope that I have experienced enough to understand the worldview of the participants in this study. On the other hand, I believe that my lack of personal experience with family caregiving will leave me far enough from the study to separate my own experiences from those of the participants interviewed. As a master's degree student in Family Relations, it has been my sincerest desire to bring what I do know about caregiving and family life to this study.

Data Analysis

The interviews in this study have been analyzed using a modified form of Strauss and Corbin's (1998) grounded theory method. Interviewer field notes were also used to help sensitize the researcher to the contextual issues surrounding the interviews, but were not used in the analysis. The use of a modified grounded theory method in analyzing

qualitative interviews allows researchers to explain a specific phenomenon without creating a theory about that phenomenon.

As Strauss and Corbin (1998) indicated, the qualitative data analysis of this study began with the process of open coding. In open coding, the interview transcriptions were read line by line. This reading of the text in a line by line fashion allowed specific elements of the transcription to be classified and labeled (Gibbs, 2007). For example, a caregiver might have spoken about the fact that her elderly mother did not always receive the prescriptions she needs because they were too expensive. This might have been labeled “limited resources for prescription drugs” or “high expense of prescription drugs.”

In open coding, when the classification is finished, the labels are then collapsed into more abstract categories. Going back to our example, perhaps other caregivers in the study indicated that they do much of homemaking chores for their elderly parents themselves because neither they nor their parents could afford to pay outside help. While individually these instances might have been labeled, “limited funds for nonmedical care” or “extra effort to cut costs of care,” these examples could also be abstracted into a broader category of “lack of financial resources for caregiving,” and included the first example of the elderly mother not receiving prescription drugs. This process of open coding continued until codes begin appearing repeatedly.

After open coding stops yielding new codes, Strauss and Corbin (1998) indicated that axial coding should then be used to develop categories and subcategories. This was done by first, laying out the properties of a category. This process involved defining a

category in its entirety. For the example above, the category, “lack of resources for caregiving” might be defined as: any action or caregiving service that might be handled differently with more available resources. After defining a category, subcategories were identified. In the previous example, subcategories for the category “lack of resources for caregiving” might have been “limited resources for medical care” and “limited resources for nonmedical care.” After subthemes are identified and defined, Strauss and Corbin then indicated that qualitative researchers should also define how the categories and subcategories are related to one another. As this was done, the analysis would be able to paint a more complete picture of the phenomena. Finally, the general categories in the analysis were examined to see if they related to one another in any way. This comparison between categories allowed the researcher to develop overarching themes that helped to describe the phenomena at hand.

Throughout the process of analysis in this study, analytic memos were used. Analytic memos are defined by Strauss and Corbin as “the researcher’s record of analysis, thoughts, interpretations, questions, and directions for future data collection” (1998, p. 110). The use of memos is an important part of the analytic process that allows researchers to document this process throughout the study. The data for this study was coded and analyzed in NVIVO, a computer software program designed for the analysis of qualitative data. In addition to analyzing qualitative data, NVIVO (2008) stores and organizes data for the qualitative researcher.

Issues of Reliability and Validity

In any research study, the issues of validity and reliability are a concern. Although

not as easily defined as reliability and validity in quantitative studies, Creswell (2007) indicates that qualitative researchers can use various techniques to ensure that the analysis of their data is as close to the truth as possible. For this thesis, the issues of reliability and validity were addressed via peer debriefing, clarifying researcher bias, and a discussion of the preliminary coding scheme with another researcher in order to resolve differences of opinion in regard to the analysis of data. When differences of opinion arose, the data was reread and then discussed to clarify any remaining discrepancies.

The use of a peer debriefer allows for greater validity in a research study (Creswell, 2007). Creswell defines peer debriefer sessions as an opportunity for the researcher to be questioned about methods, meanings, and interpretations. This also allowed the researcher to voice concerns and state feelings surrounding the research. In these sessions, both the peer and the researcher kept notes for a written account of the time spent in the session.

As addressed above, being aware of researcher bias from the beginning of the study is an important way to make sure that the analysis of data is valid (Creswell, 2007). This has been outlined for readers earlier in this chapter in an effort to enlighten readers on any potential underlying prejudice or preconceptions. Before beginning the study the researcher wrote a personal narrative to better understand her own personal feelings and biases connected to long-term care. As the data was analyzed, the researcher referred back to this personal narrative in order to keep in mind the ways that she had been taught by her family to respond to caregiving situations and problems. Doing this allowed the researcher to be introspective and critically think about any potential bias problems while

analyzing the data.

After a preliminary coding scheme was identified, the researcher met with another researcher to discuss possible differences of opinion before additional coding of the study took place. Creswell (2007) recommends that this is done to ensure that the analysis of data is reliable. This communication continued both formally and informally throughout the analysis of the data, with the second researcher posing questions and reviewing the evolving coding scheme periodically.

CHAPTER IV

RESULTS

This chapter uncovers the experiences, attitudes, and feelings of 30 family caregivers who are caring for an elderly parent or relative in the home. Each participant was interviewed once or twice and the data were analyzed in order to understand the types of services family caregivers used and how they financed those services. In addition, over the course of the interviews, participants gave voice to the feelings and attitudes surrounding the issue of personal financing of long-term in-home care. The findings for research question number one will be summarized in text and table format while research questions numbers two and three will be reported with the use of excerpts from the participants' interviews. Various participant quotes are identified at the end of each quote. For example, 1A means the quote came from participant number one's first interview. Similarly, 2B would mean that the quote came from participant number two's second interview and 3AB would mean that only one interview was held with participant three and the quote came from that interview.

Research Question 1

Elderly care recipients in this study were all receiving some form of service in addition to family care to assist them with their needs. However, each care recipient and their family caregiver faced a unique set of needs and challenges. Some care recipients had few health problems while others had many health problems like congestive heart failure and dementia. Reflective of this, the needs of the elderly care recipients in this

study ranged from minimal support to high levels of support. Elderly care recipients attending the local Senior Center often needed less support, only requiring family help with medications or paying bills, while other care recipients in the study required high amounts of support from various services like home health aides, home health nurses, physical therapy, cleaning assistance, and adult day services.

Participants in the study utilized several different home- and community-based services. Of those services, home health aides were the most often used. Sixteen of the 30 participants indicated that their parent or elderly relative was using home health aides. Similarly, 12 of the participants used physical therapy for an elderly relative and 11 noted that their parent(s) were using home nursing services. Seven of the participants indicated that the recipient they were caring for used adult day services and five were using assisted living. The least used services included cleaning services (4 of 30), nursing homes (4 of 30), senior centers (2 of 30), and other services like respite, Meals on Wheels and live-in aides.

Funding sources for the various services tended to be slightly grouped by service. For example home health nurses and aides were generally funded by Medicare, the care recipients' funds, or Medicaid. Similarly, physical therapy and hospice were funded by Medicare and Medicaid, while assisted living and cleaning services were typically funded via care recipient funds. Besides Medicaid and Medicare, other organizations like Senior Centers, the Bear River Association of Governments (BRAG), and other programs like the State Alternatives (Utah) program also helped to fund some of the services used by the elderly relatives of participants. Out of the 30 cases, thirteen of the care recipients

either funded part or all of the care services they were receiving. Additionally, only 3 of the 30 caregivers helped to pay for services; however, several indicated that they helped to provide some basic household supplies. Table 1 provides a detailed summary of the types of services used by care recipients in each family, and the ways in which they were financed.

Table 1

Common Services and Funding of Home Based Care

Participant	Services used	Funding source
1	Home health nurse	Medicare/care recipient funds
	Hospice	Medicare
2	Home health nurse	Medicaid/Medicare
	Hospice	Medicaid/Medicare
3	Home health nurse	Medicaid/Medicare
	Physical therapy	Medicaid/Medicare
	Assisted living	Care recipient funds
4	Cleaning services	Care recipient funds
	Home health nurse	Care recipient funds
	Nursing home	Medicare
5	Hospice	Medicare
	Respite	Medicare
	Home health nurse	Medicare
6	Meals on Wheels	
	Physical therapy	Medicare
7	Adult day services	Medicaid
	Home health aide	Medicaid
8	Senior center	
9	Nursing home	Medicare
	live-in aide	Caregiver funds
10	Adult day services	
	Home health aide	Medicaid/Medicare
11	Home health nurse	Medicare
	Home health aide	Care recipient funds/Medicare

(table continues)

Participant	Services used	Funding source
	live-in aide	Care recipient funds
12	Home health nurse	Medicare
	Adult day services	State Alternatives program
13	Physical therapy	Medicare
14	Cleaning services	Care recipient funds
	Senior center	
	Home health aide	Medicare/care recipient funds
	Adult day services	Caregiver funds
15	Physical therapy	Medicare
16	Assisted living	Care recipient funds
17	Home health aides	State Alternatives program
	Assisted living	Care recipient funds
	Nursing home	Medicare
	Home health aide	Medicare/care recipient funds
	Physical therapy	Medicare
18	Cleaning services	Care recipient funds
		State Alternatives program/care recipient funds
	Adult day services	recipient funds
	Physical therapy	Medicare
19	Home health aide	Medicare
	Home health aide	Medicare/care recipient funds
20	Physical therapy	Medicare
	Home health aide	Medicare/care recipient funds
	Physical therapy	Medicare
21	Home health nurse	Medicare/care recipient funds
	Assisted living	Care recipient funds
22	Home health aide	Care recipient funds
	Adult day services	
23	Home health aide	
	Home health aide	Medicaid
	Home health nurse	Medicaid
	Cleaning services	BRAG
24	Physical therapy	Medicare
	Nursing home	Medicare
25	Hospice	Medicare
26	Assisted living	Care recipient funds

(table continues)

Participant	Services used	Funding source
	Rehabilitative center	Medicare
27	Physical therapy	Medicare
	Home health nurse	Medicare
	Home health aide	Medicare/care recipient funds
28	Home health nurse	Medicare
	Physical therapy	Medicare
29	Live-in aide	Caregiver funds
	Adult day services	State Alternatives Program
	Home health aide	State Alternatives Program
30	Physical therapy	Medicare

Research Questions 2 and 3

This section addresses the willingness, ability, and reasons why family caregivers chose or choose not to pay for the long-term care of an elderly adult. In order to form a complete picture of the realities involved with the financing of long-term parent care, research questions 2 and 3 will be addressed together in this section. Both of these issues will be discussed below.

Willing or Willing and Able

While many of the caregivers in the study stated that they would not be able to pay for all of the long-term care their parent receives, most of the caregivers asserted that they would be willing to do what they could to make sure their parent receives necessary care. Of the 30 participants in the study, 24 stated this willingness. How caregivers talked about their willingness to pay for long-term care will be discussed. Reasons given for this willingness will also be discussed.

Willingness-I'll Do What I Can

As noted earlier, most caregivers in this study did not have to pay for long-term care from their own funds. Instead their parents were able to pay for long-term care from their own funds, or various government programs and organizations picked up the program's expenses. However, when asked what they would do without such funds and programs, many caregivers indicated that they would do everything they could to pay for care. This is illustrated by one woman overseeing the care of her mother who was using adult day services, physical therapy, and home health aides. She stated, "My brother and I said 'whatever it takes, we'll do it, we'll just come up with the money somewhere,' both of us will contribute . . ." (19A). Later, this same participant indicated that, "I know that my brother and I would do whatever we needed to do so that she would be taken care of" (19B). This conviction is a common thread throughout many of the participant interviews as they, like this daughter who had been caring for her elderly mother for three years, affirm that, "You know, we do what we need to do" (14A).

For most caregivers the personal payment of long-term care was a hypothetical situation. However, for others it was a reality. In these situations, the willingness of caregivers to pay for long-term care was apparent. One such caregiver, in the 5 years she had been helping to care for her mother-in-law's ever increasing needs, had learned how to work with her husband's three siblings to pay for care. She discussed this in the following comment, "Each member of the family divides it equally. . . . there's just the four of us. . . . [I]t was just a decision we all made and I don't think it hurts to contribute and make sacrifices for family. I'm willing to do it" (10B).

Enlisting family help. Many caregivers indicated that when paying for their parents long-term care costs, they would enlist the help of siblings and other family members. In many cases, these caregivers asserted that before they paid for care themselves, they would ask family members to help as well. One woman who had overseen the care and use of physical therapy services of her mother stated that, “I would talk with my brothers and sisters and maybe we could get together, some from everyone and put it all together to pay for all those services” (29B). Another participant that had been caring for her elderly mother for over two years asserted, “I would call my siblings and if it cost more than her [mother’s] income, she has a small income, I think we would all contribute to have her continue [with services]. . . ” (7A). When asked what she would do to continue nursing services for her father if he could not pay for his own care, another caregiver indicated that she could not pay for his care on her own. However, with the help of her siblings they could pay for the care of her father. This is illustrated by the following comment, “I couldn't afford what he pays [for nursing services]. I would go to my brothers and sisters, and we would all have to chip in. Then I think it would be doable. But I personally could not do it alone. . . ” (28A). Similarly, when asked who in her family she would ask to help pay for the services an ailing mother, another participant stated,

Everyone. Everyone. Nieces, nephews, her grandchildren, my brothers, my sisters, my aunts and uncles, my aunts' and uncles' children. It doesn't matter, everyone. Anybody I needed to ask. And until I got the answers I needed, I would ask (1B).

Personal sacrifice. While many caregivers expected their siblings and family members to help pay for long-term care, others indicated that they would make extreme personal sacrifices to care for their parents. The following exchange exemplifies this idea,

Interviewer: How much do you think that you would be able to contribute, or that you'd be willing to contribute?

Participant: *I probably couldn't afford more than about \$300 a month at this point. But like I said, I'd just declare bankruptcy and take care of her, or just tell the creditors, I'm sorry- you have to wait if you want your money, otherwise. . .*

Interviewer: The care is that important to you? And your mother is that important to you?

Participant: *Yeah (19B).*

Another participant who was using his mother's farm to generate an income to pay for her assisted living care demonstrated this as well. He stated, "I don't know how I could do it [pay for care]. I don't. . . . I guess I would just say, Here, come and get my home, my farm. . ." (22A). Yet another participant indicated that her husband would take on a second job to help pay for her mother's care (29B).

Motivation to Pay for Care

Aversion to nursing home care. Among participants, several indicated that either they or their parents had an aversion to nursing home care. Often, this aversion came from a desire to honor their parents' wishes for their own care. One caregiver who had moved from Texas to Utah to care for her mother-in-law stated, "The only other option that was available was sending her to a nursing home and she has told us enough that she

doesn't want to go there unless she absolutely, positively has to" (3A). Similarly, another caregiver who had been providing full-time care for her mother for over ten years and more recently started providing part-time care for her in-laws commented,

Participant: *She [mother] doesn't want to go to an old folks home, if you mention old folks home, you're in deep trouble.*

Interviewer: So she doesn't want to go there?

Participant: *No, if she went there, she wouldn't know me anymore. She'd disown me* (11B).

In addition to wishing to honor their parent's desires, several caregivers also had their own reasons to avoid nursing homes when possible. One caregiver who had started an adult day center, and had been caring for her mother for seven years spoke of recent episodes with nursing home care for respite services. She stated,

I also take her to rest homes occasionally for short periods of time. We went to Mexico one Christmas for two weeks and I put her in a rest home. But I have had her in a lot of different rest homes and I don't think—she comes home and she is all black and blue. I pick her up and her diaper is, you know, all messy. And she doesn't get very good care in rest homes—none of them. I don't like rest homes (15A).

In addition to wishing to provide quality care to their parents, it was the personal desire of some caregivers to have their parents stay in their own homes. One woman who had cared for her mother and was more recently caring for her father indicated, "It was really neat to have Mom die here [at home] and that is the way I want him to do it" (2A).

Financing and economic issues were also reasons for caregivers to avoid the institutionalization of elderly parents. Caregivers noted the high cost of nursing homes and opted to pay for at home care instead. One participant stated, “If somebody required full-time nursing care at \$3,000 a month and you had a mother and a father and they were suddenly trying to drain an income of \$6,000 a month, we're talking pretty big dollars” (23AB). Another caregiver who, with the help of siblings, was paying for in home care noted,

Yes, there were other options, but the other option was to have her be a resident of the [nursing home], but she doesn't have any money and I know that's very expensive. . . . We decided as a family to try and hire someone and keep her in her home as long as we could and care for her the best way we could. . . . So for financial reasons, we decided to do it this way (10A).

Family expectations and responsibility. Many of the family caregivers in this study felt that family expectations and responsibility were the driving force in their decisions to pay for long-term care. One caregiver, who was helping to care for both her own parents, and her husband’s parents asserted, “We need to take care of our own” (23AB). This sentiment was echoed by several others. One such caregiver was a woman who was overseeing the care of her parents, both of whom had dementia and were in assisted living. She indicated, “I think family should take care of family” (16B). Another woman who was also caring for her father in assisted living indicated, “I just think we have to take care of our parents. That is just something that we are expected to do” (26B). For these family caregivers, it was not a choice of whether or not to pay for care. Caring

for family is part of one's role as a family member.

Some caregivers talked about caring for family as if it was a sort of innate commitment. One woman had been providing care for one or both of her parents for over 13 years. She stated, "It was kind of like a preordination. . . . I have always known that it was my job" (28A). Similarly, when asked where this sense of familial duty comes from another caregiver indicated, "I don't know, I guess it's something you're born with, inherited, you just feel like you have an obligation to do it" (22B).

This sense of obligation to pay for the care of family was important to many caregivers who felt that families should care for one another and not pass that obligation to someone else. One woman had been traveling between Oregon and Utah for five years in order to oversee the care of her mother who was receiving home health services. She asserted,

Mom has always been very, very independent so I know that this would be very hard for her to know that somebody else was having to pay for her care and . . . to me it feels [like] 'We're doing it, we're not giving the responsibility to someone else.' As long as we can. And we may need a little bit of help [but]. . . we can do the rest (12B).

For some caregivers, paying for the long-term home care of a parent was the responsibility of the children (6B). However, for others, paying for long-term care was the responsibility of the entire family. After caring for her mother-in-law for over 6 years, when asked whose responsibility it is to pay for long-term care one caregiver responded, "The family, the whole family" (30B). Another caregiver detailed this in the following

example:

I think it should be all the children [to pay for care], and I'm sure there are times when they can't and then I think that it can reach out to the grandchildren. . . . I think it is, I think the first responsibility is the family (12B).

Moral and religious responsibility. Although closely connected to family values, religious and moral responsibility was another reason cited by caregivers to finance parent care. All but one of the caregivers in this study were members of The Church of Jesus Christ of Latter-day Saints (LDS). Deeply linked with the LDS faith is the value of family. This is because, in LDS doctrine, "The family is ordained of God" (The Church of Jesus Christ of Latter-Day Saints, 1995). One caregiver referenced her religious beliefs when speaking about funding long-term care for her parents,

But our family. . . I think it stems back to our religion, which is LDS, that if you can take care of and help each other in your family, that's what we are supposed to do before we exhaust those other [financing like Medicaid] means That's how I've been raised; how our family has been raised, we are taught to take care of each other (10B).

Another caregiver indicated that caring for parents is taught by LDS church leaders when she stated,

Well you listen at conference [semi-annual religious meeting of the LDS church] and they tell you it's your responsibility to take care of your parents and stuff, and it just seems like something that ought to be done. They took care of me when I was little, I should take care of them (11A).

More commonly however, rather than referencing religious responsibility, caregivers discussed the moral responsibility of helping to pay for long-term care for their parents. Caregivers spoke of the moral right and wrong of helping to pay for the care of parents versus refusing to help care for parents. A comment from another participant illustrates this. This participant was a professional in the long-term care field as well as a caregiver to her stepfather. She stated,

You have to do it [pay for care]. Whoever can. If Mom can afford it, then great.

If Mom can't, then the family. What are you doing to do, let her sit there?

Without care? I see it happen every day. I think it is morally wrong. I mean, it is not something that we condone in our family (1B).

In addition to moral right and wrong, many caregivers indicated that if they did not provide financial support in caring for their parents they would have to live with internal feelings of remorse. After her father died in a car accident, one woman began caring for her mother full time. Her mother was completely blind, confined to a wheelchair and had diabetes. This caregiver described the moral dilemma that she went through in the following comment,

I just considered it the moral thing to do. The only reason I had to not do it was selfishness and that didn't seem to be reason enough, just some kind of false idea that I would be able to do what I wanted to do, go my own way and do my own thing and be entirely selfish, I don't think so. That was really the only reason not to because I didn't have any really profound reason to avoid helping her, it wasn't like I couldn't physically or financially or emotionally, that just left me with being

selfish and I didn't want to be that kind of person (13B).

Legacy of family care. Many participants indicated that maintaining a strong legacy of family care was an important reason to pay for long-term care. Throughout the interviews, participants discussed the legacy of family care in two ways, through reciprocity and the transmission of values from one generation to the next. When participants discussed reciprocity, they often cited ways in which their parents had cared for them throughout the years. Typically the transmission of values from one generation to the next is discussed when participants noted that their parents had taken care of their grandparents when they were elderly adults. For these participants, caring for their elderly parents was not just the right thing to do; it also allowed them the opportunity to perpetuate the family legacy of care.

For some, providing financial and other support for long-term care was a way that they could reciprocate the care that they had received from their parents throughout the years. Some felt they were obligated to their parents, like one participant who said, "I love my mom, she's always been so good to me that I feel like I owe her, that's it" (6A). Others felt that paying for long-term care provided a good opportunity to reciprocate care they had received throughout their lives, "It has really been quite a privilege. She took very good care of me for many years and I feel it a privilege to do the same" (15A).

Caregivers often referred to the fact that they learned to care from their parents who had provided care to older generations at an earlier point in their lives. One caregiver who shared caregiving responsibilities with one of her six sisters discussed,

When I was young at home my grandmother lived with us. She lived with one of

her kids for three months and then she would go to another one for three months and we got real close. In fact, grandma slept in my room with me, so we were used to helping take care (6A).

Through watching their parents provide care to grandparents, these caregivers felt a sense of responsibility to do the same.

In addition, participants noted that in some cases their parents specifically stated that they expected them to care for them because they had cared for their own parents or other family members in the past. One participant whose mother was in assisted living recalled a conversation with her mother, “She once said, Well I took care of grandma and I took care of my mother-in-law for a little bit, and I guess it is now your turn to take care of me” (25A).

Not only were these caregivers motivated to provide care because of what had happened in the past, but some were looking on to future generations. These caregivers felt that it was important to care for aging parents in order to teach their children the value of caring for family. One mother stated,

What are you going to expect if you don't teach your children by your example of taking care of your own parents? Who is going to take care of you? Because this is a taught thing. You don't just jump in and say, Well, I've never seen anybody take care of their parents before, but I am going to care for mine. No. You see your own parents do it. And you know that it is expected. It is a learned behavior. So whoever can, that is who pays for it (1B).

By providing an example for their children to follow, these caregivers were not only

continuing on with the legacy of care their parents had started, but they were helping to perpetuate it by teaching their children to do the same.

Unable to Pay

Although some of the caregivers in this study felt that they would be able to financially contribute or pay for the long-term care of their parents, many felt as if they were unable to do so. Fifteen of the 30 participants stated that they could not afford to pay for the long-term care of an elderly parent. It is important to note that many of these same caregivers were willing to pay for care, as discussed above, but lack the necessary resources to do so.

Inability-finding other paths. Among participants, inability to pay for the long-term care of a parent is a pervasive issue. One woman who had gone through the process to hire an aide to cook for her mother stated, “As far as paying for it [long-term care] out of my own pocket, I am not in a financial position to do that” (14B). Another participant had been caring for her mother and father for three years. When asked if she would be willing to help pay for the long-term care services of her mother she stated, “Moneywise, well I probably couldn’t contribute a whole lot” (21B). Similarly, another caregiver who had been caring for her paraplegic father for over six years indicated, “There is no way I could [pay for services]” (24B).

In many cases, caregivers felt that by contributing financially to the long-term care of their parents, they would subsequently create other financial problems in their families. One caregiver provided the following comment that illustrates this issue,

Interviewer: So would you consider it [paying for long-term care] if you had to?

How much do you feel you would be able to contribute?

Participant: *Out of our personal income? Not very much, not very much.*

Interviewer: You think the strain would be too great?

Participant: *Yep, it would (22A).*

Use of unpaid service. Regardless of their financial situations however, several caregivers indicated that although they did not have the money to pay for long-term parent care services, they would still make sure their parent's needs were met. One caregiver affirmed this when she said,

There is no way I could have paid for it [long-term care services] myself. I don't have the income. I don't have the means. I could have lived in with them. But I could not have hired out the P.M. help. We would have just had to have done it ourselves, or have my nephew do more (1A).

For many caregivers, a sudden lack of financial resources, or an inability to pay for long-term care services would initiate a greater use of family and volunteer work. The following is an example of this greater use of volunteer work and family effort:

Interviewer: Would you hire somebody privately do you think?

Participant: *No, I don't know that I would be able to afford to hire anyone to come in, I'd probably have to talk to the Bishop and see if some of the older sisters in the ward or some of the neighbors could come from time to time and talk with some of the family and see what arrangements, where they could come by and help and work it out that way.*

Interviewer: So you'd make something happen?

Participant: *Yeah, you'd have to make something happen, [you] can't sit her on the porch and leave her there.*

Personal Obstacles to Help Pay for Care

The inability of family caregivers to pay for long-care stems from several concerns. These concerns may be not having a job, not having enough income, experiencing a difficult harvest season on the farm, not being finished with college, not having enough support from siblings or other related concerns. Of these various issues, two of the most pervasive will be addressed. They were limited family support, and age-related personal obstacles.

Limited family support. Caregivers in this study indicated that they had family members who were, in some cases, unable to assist them in paying for long-term parent care. When asked if her sisters would be able to contribute to the payment of long-term care for her mother, one caregiver asserted, “No. Neither of them has the resources.” In contrast, other caregivers indicated that their family members would be unwilling to assist them in paying for long-term care. Between unwillingness and inability, lack of family support played a role in the ability of caregivers to pay for long-term care.

When discussing the unwillingness of family members to help pay for care, one caregiver asserted, “That’s a closed door . . . they [family members] wouldn't or couldn't [pay for long-term care]” (23AB). Similarly, another caregiver who had given up a well-paying job to care for her aging parents stated,

They [family members] are terribly, terribly afraid that they will have to be obligated to pay for things. And so that is why we took out the reverse mortgage

and that is why [sister] has got such a tight hand on what we do with that money (2B).

Feelings of anger and resentment are perhaps the most notable outcomes associated with the unwillingness of family members to pay for long-term parent care. One participant who was caring for her husband's aunt spoke with bitterness about the unwillingness of family members to help pay for care.

Interviewer: If the time came that more funding was needed, and if they were asked to participate, what would they say?

Participant: *We can't.*

Interviewer: Is there a possibility they could participate some?

Participant: *No.*

Interviewer: Do you see it as mostly a lack of resources or is it another issue with them?

Participant: *I think it is selfishness, to be honest with you (5B).*

In some cases, caregivers had no family to ask for additional assistance in paying for long-term care. Three of the participants in this study were the only children of elderly parents. One of these participants talked about the financial strains of paying for his mother's care alone. He stated, "It is a drain on me. If I can put it into words, as far as taking care of her, I'll do that for as long as it takes, that doesn't bother me. It is meeting the financial obligations" (22A).

Personal obstacles. Participants in this study indicated several different personal obstacles to paying for long-term care. Many of these obstacles were age-related

obstacles to the payment of long-term care. Personal obstacles typically cited include caring for parents and children at the same time, poor health, and limited retirement funding.

Of those caring for multiple generations, when asked if she could help to pay for long-term care, one caregiver asserted that she couldn't because, "I have three kids in college!" (23AB). In contrast, some caregivers spoke of the difficulty to pay for long-term care when needing to still plan for retirement themselves. One caregiver had a mother and father utilizing nursing home care and assisted living. She indicated,

If they [parents] didn't own property and didn't have anything, I don't know [if I could pay for care]. Most of us in my age bracket, we don't have that much that we could have it set aside to take care of ourselves plus take care of aging parents, so it would be double (18B).

Similarly, another caregiver spoke of how her retirement limits her ability to pay for long-term parent care. She asserted, "I'm on civil service retirement money, so I don't have a lot of money" (24B). Another caregiver spoke of being limited in the funds she could provide because of medical issues connected to being an older adult, "My husband is seven years older than I am and in poor health, and I am limited on what I can do, and our medical bills are very, very high" (18A).

Payment is Unnecessary

Of the reasons given not to pay for long-term care, caregivers often noted the fact that care recipients were able to fund their own care, thus nullifying the need for them to provide from their own funds. Care recipients ability to fund their own care was indicated

by 13 out of the 30 participants as a reason that they did not pay for long-term care. One caregiver asserted, “They [parents] have a fairly good income, they’re very self-sufficient” (20A). This same participant, in talking about her father stated, “He was very wise in using his money when he was in business and invested in these apartments. I think they’re financially okay through the rest of their lives” (20A). By having these funds, care recipients relieved their children of any financial difficulties. One caregiver stated,

Well, we haven’t had to provide any of it [money for care]. You do things, you buy milk and you do a lot of stuff that you just take up to them [parents] and don’t think about it. But we haven’t had to bear any of the [financial] burden on it at all (18B).

In addition, caregivers indicated that their parents had worked hard to save for their long-term care. In talking about her family’s reluctance to use Medicare, one caregiver stated,

My parents worked real hard all of their lives to save money for their old age, and there are other people that need Medicare, where my parents have the money to pay for it. That is what they saved their money for. I am not real keen on the government paying for everything for everybody. There are people who need that, and so the money should be there for those who really need it (16A).

Similarly, several caregivers did not mind if all of the money their parents had saved went towards long-term care. In speaking of her mother, one caregiver asserted, “Yeah, Mom has enough money that she can [pay for care] even if it takes every penny

that she has. I want her to be happy and to have the help and not feel like she is so dependent on us” (21A). Another caregiver, in speaking of her parents funds stated, “It is theirs and that [caregiving services] is what it is to be used for” (18A).

Family Relationship Factors Surrounding the Provision of Care

The impact of family relationships on the attitudes that surround the payment of long-term care has yet to be addressed. All of the 30 participants in this study referenced different forms of family relations when speaking of long-term care. However, none of the caregivers cited family relationships (positive or negative) as a direct cause or reason to pay or withhold payment for long-term care. Instead, these family relationships seem to be underlying, indirect factors influencing the attitudes surrounding the payment of long-term parent care. The most common family relationships discussed by participants in this study include sibling relationships, caregiver-care recipient relationships, and spousal relationships. To better understand how these relationships might influence the willingness of family caregivers to pay for care, each of these relationships will be discussed below.

Sibling Relationships

Sibling relationships were the most often discussed of all the relationships referenced by participants when talking about parent care. Throughout the interviews, participants typically had sibling relationships that were divided into those who had positive and negative relationships with their siblings surrounding long-term care. Typically, those whose siblings provided actual or (when not in a position to give actual

support) moral support were those who had positive care relationships. One caregiver recalled a conversation with her brother who lived in another state.

And he said, 'Sis, I hardly do anything'. And I said, 'You know it is the little things that count.' And I said, 'You do the little things that I just can't do, and I really appreciate it,' and he said, 'Well I really appreciate you, what you are doing, because I can't do what you are doing.' So I said, 'Good, we are kind of a team' (16B).

Another caregiver who was caring for her mother talked about the things her siblings did to support her caregiving efforts. She gave an example,

They give a lot of moral support, then when I'm gone they come and I make out a calendar and put the times of who is going to be, and sometimes at our reunion we just pass the calendar around and my brothers take in and fill in the times they can come [to stay with mother]. (12A)

Not all caregivers felt this kind of support from their siblings. One such caregiver discussed her resentment for the excuses made by siblings to not help with care. She stated,

. . . I was the only single child. They all have families. Quote, unquote, families. [a hint of cynicism and laughter] . . . They want to do it but they [say] I've got these obligations. [laughs] I have a family. I hate that statement, you can tell. (2A)

In addition, families who seemed to be working smoothly together to provide care also sometimes felt relationship strain related to care. One caregiver, whose in-laws had

worked together to hire an in-home aide for their mother related the following experience,

The other oldest daughter, would sometimes bring her (care recipient) over and I would leave work so we'd go to the doctor's office but she could never go in with her. She just said, I could not deal with it, I don't do old people. [Sister-in-law] is a wonderful lady but I sometimes resented that because I thought this is your mom and older people, geriatric patients aren't my cup of tea either but somebody has to do it. (10A)

Caregiver-Care Recipient Relationships

Throughout the study, participants discussed the relationships they had with their elderly relative. For most, this relationship was a positive one that made providing at-home care easier. One woman, whose mother-in-law was attending adult day services stated, "But you know, I want to reiterate that it's not a burden for me, I love this lady and this family and it's my husband's mother . . ." (10A). Later, this same caregiver referenced that her mother-in-law's personality was a large factor in their positive relationship. She indicated, ". . . I don't resent helping [mother-in-law] because she's such a sweet lady, always kind and apologetic" (10B).

In contrast, a few caregivers indicated that their relationship with, and the way they felt about their parents, was less than a positive thing. One caregiver noted the selfish attitudes of her mother-in-law when she made the following comment,

A lot of it is just her own personality . . . she has always been pretty much self-serving and self-centered. . . . And we are here to help her, but then she turns

around and treats us like dirt. So it is hard to deal with, it really is. (4B)

Another caregiver made a similar comment about her mother-in-law, referring more directly to financial matters,

You know, that probably doesn't help the feelings with someone like that who has lived her life in a way that has spent all the money doing whatever she wanted to do, with kind of the attitude of, [son] will take care of it. [Son] will take care of me. Not making sure there was life insurance to cover, or trying to save, or anything like that, it was just, you know. She lived better than we do; they were in the country club and stuff when I met them. They had all their friends and parties and stuff like that, which we have never done. We've tried to live within our means. (22B)

Spousal Relationships

Many of the caregivers in this study asserted that their spouse was one of their greatest assets in their journey of providing care for an elderly relative. One woman, who had started a successful adult day center in her mother's name stated, "[Husband] has really proven his mettle in helping. I would not have taken on this challenge of the day care center if it had not been for his support. He was doing the books for me" (15B). Similarly, many others felt that they would not be able to provide care for their parents if they didn't have a supportive spouse. One caregiver asserted, "My husband is wonderful, I couldn't do it if it wasn't for him" (21A).

However, regardless of the support they were receiving from their spouses regarding care, there were still a few caregivers that indicated that sometimes their spouse

had a difficult time being supportive. One caregiver who had been providing care for over 13 years stated, “Every once in a while, he [spouse] will be resentful because you know there is somewhere he wants me to go for a weekend, or there is something he wants. . .” (28B). Another caregiver indicated that her husband was jealous of the time she spent caring for her mother (11A). Although some caregivers experienced these issues, the majority of the caregivers in this study asserted that their spouse was generally very supportive of the care they were providing.

Creating a Context: A Case Study

This section addresses the fact that family caregivers each have unique situations and highly interconnected reasons to pay for long-term parent care. When taken out of context each of the reasons discussed above may not fully explain the willingness, ability or the stories of caregivers who are faced with the decision to pay or not pay for long-term care. By taking into account the various personal and organizational relationships of long-term care, an ecological framework allows for a greater contextual picture to emerge. To illustrate the concept of a greater contextual picture, a case study is presented. This case tells the story of a daughter-in-law, her spouse, and her husband’s three siblings who are collaborating to provide care to their mother/mother-in-law. Although this case was not typical of the majority of families in this study, it does an excellent job of illustrating the connections among family caregiver, extended family members, and meso systems like medical and service providers as decisions are made about the elderly parent’s care and it’s financing.

Working Together to Pay for Care

Rose was a sweet and kind mother, mother-in-law, and grandma. Her children and grandchildren knew that if they ever wanted treats like cookies, hot rolls, or cakes all they needed to do was stop by Rose's tidy little home. Rose was never rich, but always made an effort to be there for her family. That was part of why Janet loved her so much. They were a close family, all four of the kids and the in-laws, and got along very well together. That is why Janet worried when Rose began to call her crying, "Can you come help me make my cookies or help me roll them out? I can't remember where my recipe is or when I start to make them I can't remember if I put three cups of flour in or two." She also worried when Rose couldn't remember if she had paid her bills for the month or if she had taken one of her many daily medications.

Because she lived close, Janet found herself helping Rose on a constant basis with her bills and medications. She would spend hours helping with these tasks and talking to Rose about her worries concerning her memory loss. One night, during the night Rose had a blackout spell. Pretty soon, Rose began to call Janet frequently during the night and complain of similar blackout spells. For the next 10 years Janet helped Rose with tasks like paying the bills, and she was there when Rose had one of her reoccurring blackout spells. However, one night Rose had a spell that was worse than any before. Janet called an ambulance and Rose was taken to the hospital. At that point, Rose's doctor, Dr. Stewart, began to be much more involved in Rose's care. Not long after, her driver's license was revoked and after a few more hospitalizations the family decided they needed to become more involved.

Because Rose was losing quite a bit of weight, the three local siblings decided that they would each take two nights a week to bring dinner in to her. During this time Rose also began attending adult day services. For the next year, they would take her meals or take her out to eat with their families and Rose would get herself up and catch the bus to attend the adult day services. However, throughout the year Janet noticed that some of her husband's siblings were becoming busy and instead of spending time with Rose, they would hire someone to bring her in a meal. Resentment started to creep into the family as Janet perceived that some of the children were more willing to make sacrifices for their mother than others.

At about this time Janet was in a doctor's visit with Rose when Dr. Stewart commented, "I don't think this family realizes that Rose is deteriorating to the point where she most likely needs someone to be with her at all times." Dr. Stewart then recommended that Janet get the family together for a meeting in his office. During that meeting he explained to the family about Rose's dementia and aging process. He also explained the kind of full-time care that Rose really needed. As the only in-law at the meeting, Janet figured that the siblings needed time to work things out on their own. She left as they started into a shouting match in front of Dr. Stewart. They argued about who has time and money to help and who does not. After a bit of time, the siblings came to a consensus. They would hire a woman to live in Rose's home with her, to cook, clean, and help with other personal care tasks.

After talking with LDS Social Services they hired a woman named Jenny. Jenny was a woman in her late forties who had no home and was looking for a job and a place

to live. She moved into a spare bedroom in Rose's home and began providing care. Although there were a few complaints about the quality of care Rose was getting from Jenny, after talking to Jenny about the problem, the family decided to continue their caregiving arrangements. The three local children still had Rose over for dinner on Sundays and checked in on her often.

As a family they decided to split the costs to have Jenny in the home between the four of them, with each of them paying out an even amount per month. They used public support only for the adult day center which was funded through a state program. Furthermore, they felt that unless they absolutely needed to do so, they would try to continue Rose's health insurance so she would only need to use Medicare as a secondary insurance for her health needs. They also felt strongly that they would not use Medicaid unless it became their only option. The siblings felt that these programs should be used for someone who really needed them. Additionally, because of what she had learned from LDS church leaders, Janet believed that families should pay for care before using government assistance (10).

Importance of Context

The case study related above provides an important example of why context is so important in a thematic qualitative analysis. In this case study, it is a relatively simple task to identify several reasons that the family chose to pay for the long-term care of their mother/mother-in-law. Religious and moral values, busy schedules, the influence of a health care professional and other variables may all have played a role in the decision to have the family pay for an in-home aide for Rose. This is important because busy

schedules may not be enough of a reason to pay for care, but the interaction of busy schedules, moral values and strong family relationships might be enough of a push to influence the pocketbooks of a family. Because of this, the findings related in this story should be considered as only pieces of a puzzle rather than an entire picture.

Additionally, it is apparent that all four of the siblings in this case had sufficient funds to help finance care. Not all families would be in the situation where they could help fund care. Similarly, it is also important to note that without Janet's willingness to oversee paid caregiving situations, or to be available during crises, this family's system may not have worked. Regardless of the amount of paid caregiving support, family caregivers must still be vigilant and attentive to the caregiving situation.

Summary

As participants in this study shared their stories they provided large amounts of information that would allow for greater depth and insight into the lives of caregivers. As this data has been analyzed, questions have been answered and categories emerged. Through this process, caregivers divulged the types of home care services they were utilizing, and how these services were financed. Additionally, the willingness and ability of caregivers to pay for long-term care, and reasons for this willingness have also been identified. These research findings will be discussed in the next chapter, but provide a powerful tool for researchers and policy makers alike. As one participant asserted, "It is just that growing older is an unpleasant fact of life. The more informed you are . . . the better it is for everyone. The important thing is for everyone to just be prepared" (25A).

CHAPTER V

DISCUSSION

This study was designed to provide a better understanding of the perceptions, attitudes and actions of caregivers regarding the financing of long-term parent care at home. Qualitative interviewing and analysis was utilized to help provide this understanding. Little to no empirical research has been done on the topic of financing long-term parent care. Additionally, research that has been conducted in this area is either quantitative in nature or does not address the caregiver's attitudes and reasoning for financing long-term parent care. By addressing this study qualitatively, the voices and experiences of family caregivers are heard. Results from this study can assist researchers, clinicians and policy makers to better understand the experiences and attitudes of caregivers as they navigate the long-term care system and provide care to elderly parents. An ecological framework was used as a backdrop for this analysis. Research questions that were used in this study include the following.

1. What are the home- and community-based services that are used by the family caregivers of elderly adults? In what ways are these services being financed?
2. To what extent are family caregivers willing or able to pay for long-term parent care in the home?
3. What are the reasons that family pay or choose not to pay for long-term parent care in the home?

The analysis of this data indicated that the caregivers in this study were most likely to use long-term care services like home health aides and nurses, physical therapy,

adult day services, and assisted living. Typical funding mechanisms for these and other long-term care services included Medicaid, Medicare, care recipient funding, state programs like the state of Utah's Alternatives program, and caregiver funding. Of these funding options, Medicare and care recipient funding were the most often used mechanisms.

Participants in this study typically fell into one or more of three, sometimes overlapping categories of willingness and ability to pay for care. These categories included willing, or willing and able to pay for care, unable to pay for care, and payment for care is unnecessary. These categories tended to be non-mutually exclusive, meaning that a participant could have been willing, but also unable to assist in the payment of long-term care.

Caregivers in this study were typically very willing to do what they could to provide care for their parent. This is the case for many adult child caregivers. Radina (2007) notes that children caregivers often care for three general reasons, to fulfill family expectations, because of various emotional motivations, and to complete a typical developmental task. In this study, those who were willing to pay for long-term care cited reasons such as a high aversion to nursing home care, family expectations and responsibility, moral and religious responsibility, and a desire to perpetuate a culture of family care. These findings suggest that for some caregivers, a commitment to home-based long-term care includes a willingness to help pay for parent care, especially when parents lack funds and publicly funded options do not exist.

Although willing to pay for long-term care, many of the participants viewed

themselves as unable to assist in the funding of long-term care. However, many of those who were unable stated they would find other means to take care of their elderly parent or relative. Reasons for inability to fund long-term care among participant caregivers were usually related to a lack of family support or factors related to the caregiver's advancing age. In addition, many of the caregivers presently found it unnecessary to assist in the funding of care because their parents were able to fund home- and community-based care themselves. Both positive and negative family relationships were also connected to the willingness of caregivers to pay for care. However, these relationships were likely to be referenced by family caregivers as contextual factors, but were not cited as reasons for willingness to pay for long-term care.

Discussion of the Results

Important Findings of RQ1: Services and Financing Used

Research question one was designed to investigate the types of paid services that family caregivers use to supplement the unpaid care they are providing to elderly relatives. In addition, this research question was also designed to identify various forms of long-term care funding and how they are used in conjunction with these services. Participants were asked to report on the services and funding that they were using to supplement their unpaid family care. As expected, medical home care services, adult day centers, chore services, assisted living and nursing homes were all utilized by family caregivers in this study. These services are all common forms of home- and community-based long-term care for elderly adults.

Over half of the participants in this study were utilizing some form of medical home care services. Home health care nurses and/or aides and physical therapists were the most common providers of these services. However, there was one case in which a highly involved and dedicated doctor made house visits to the elderly adult care recipient. Family caregivers indicated that most of the medical home care services their elderly relative was receiving were funded by Medicaid, Medicare, and via the out-of-pocket monies of the care recipient. These findings support existing literature concerning the ways in which medical home care is funded (Kassner, 2006a). The caregivers in this study may have used these funding mechanisms more than other possible funding sources because they are very well known and readily available to the general public. Other funding options that are available may not have been utilized as much because of a lack of knowledge or information about the funding mechanism.

The findings for this research question support existing literature in several other ways. Participants utilizing assisted living or chore services typically paid for these services with out-of-pocket funds. This is because, while assisted living and various chore services have gained some support from governmental and other programs, limited funding still exists to pay for such services (Kassner, 2006a; Wright, 2004). In addition, nursing homes, typically only used by study participants in acute situations, were often funded by Medicare, which funds nursing home care in such situations (Feder et al., 2000; Kassner, 2006b).

Participants in this study also underutilized long-term care insurance. Of the thirty participants in the study, only one held a long-term care insurance policy which, at the

time of the study, was not being used. This reflects general trends in the larger population of long-term care recipients and their care providers. Currently, less than 10% of the population uses long-term care insurance to fund long-term care (Feder et al., 2000). The elderly care recipients in this study may have avoided using long-term care insurance because they didn't have an appropriate knowledge of the advantages of care insurance. The LDS church teaches that family members need to care for one another. Because the majority of this sample held membership in the LDS faith, care recipients may also have avoided long-term care insurance because they expected that family members would care for them as they aged.

Most of the findings for this research question support current literature. However, in contrast to the literature on long-term care, the majority of participants in this study who were using adult day services did not pay for these services out of their own or the care recipients' funds. Instead these services were often paid for by the Utah State Alternatives program or by grants from other organizations. This finding may be due to the fact that all the participants in this study were utilizing the same adult day services center. While this center provided grants and funding options to clients, this likely is not the case with every adult day center.

In conclusion, family caregivers and their care recipients use a variety of long-term care services offered in the home and community settings. These services were typically paid for through various state and federal programs like Medicare, Medicaid and the Utah Alternatives program. Care recipients and their caregivers also help to fund these services via out-of-pocket monies. The findings for research question number one

generally support current literature surrounding the financing of long-term care.

*Important Findings of RQ 2 & 3:
Willingness and Reasons to
Finance Long-term Care*

The aim of research question two was to understand how willing and able family caregivers would be to pay for long-term parent care. Additionally, research question three was designed to better understand the reasons behind these attitudes and levels of ability to pay for parent's care. This study included these questions because limited research exists to explain the willingness, ability, and reasons why caregivers to pay for the long-term care costs of an elderly relative. This study helps researchers to understand these caregiving attitudes as well as the reasons for them. While analyzing the data for research questions two and three, several important findings emerged. These findings will be discussed in the context of three categories. These categories include those who are willing, those who are unable, and those who find it unnecessary to pay for long-term parent care. Discussion about the indirect influence of family relationships on these attitudes also is addressed.

Willing to pay for long-term parent care. The findings of this study suggest that most family caregivers were willing to help pay for long-term parent care. None of the caregivers in this study noted that they were unwilling to pay for long-term parent care in the home. This may be due to the fact that caregivers who are unwilling may feel it is socially unacceptable to recall these attitudes to a stranger in an interview. Regardless of this possibility, most of the caregivers indicated that they were willing to do what they could to help pay for the long-term care costs of keeping their parent in the home.

One of the most pervasive reasons to pay for long-term care in the home was a desire to keep elderly care recipients out of nursing homes. More than a third of the caregivers indicated that they or their parent(s) had an aversion to nursing home care. Indeed, many caregivers were willing to do whatever they could, including paying for care services themselves, in order to honor their parents' wishes for care. This finding is consistent with current literature that states that most elderly adults desire to stay in their homes for as long as possible and that their children do what they can to honor these wishes (Gibson, 2003; Piercy, 1998; Wright, 2004).

In addition to a desire to keep parents out of nursing homes, participants in this study also discussed having a family responsibility to pay for long-term parent care. Most caregivers cited familial reasons to pay for care; often referencing family expectations to pay for care, feelings of obligation to parents in order to reciprocate past caring situations, and a desire to continue and pass on a legacy of family care because their parents had cared for grandparents or other family members in the past. These feelings of family responsibility may also reflect the influence of the LDS religious culture on caregiver attitudes surrounding care of family members. Nevertheless, these findings support and add to the literature surrounding filial responsibility and strong caregiving commitments. Filial responsibility is a personal sense of obligation to care for ones' aging parents (Blieszner & Hamon, 1992). This finding adds to the literature by expanding the current definition of filial responsibility to include financial aspects of long-term care for some adult child caregivers.

Caregivers in this study also commented on the religious and moral responsibility

they felt to help pay for the long-term care of their parents. As mentioned previously, all but one of the caregivers in this study was a member of The Church of Jesus Christ of Latter-day Saints (LDS). As caregivers spoke of their willingness to pay for long-term care, a few discussed the counsel from LDS church leaders to care for elderly parents. In doctrine, LDS church leaders counsel members to honor their parents by caring for them (Oaks, 1991). For some caregivers in this study, this counsel was a reason to fund the long-term care of parents.

While a few participants cited religious beliefs, many others were more likely to reference their own personal moral beliefs. In these cases, moral responsibility was a large factor in their willingness to pay for long-term parent care. These caregivers were willing to pay for long-term care out of their own pockets because they felt that doing otherwise would be against their personal values. This finding brings to the extant literature a new understanding of the role that religion and individual moral beliefs can play in the willingness of caregivers to fund care. However, this finding may not generalize to all family caregivers given the high percentage of LDS church members in this study. Despite this limitation, most caregivers, religious or otherwise may feel similar moral responsibility. Thus, additional research needs to be conducted to explore this issue more fully.

Unable to pay for long-term care. While still willing to pay for care, many of the caregivers in this study asserted that they were unable to pay for long-term parent care on their own. Caregivers cited several reasons for this inability to pay. One of the most common reasons given was a lack of financial support from family members. Siblings

and other family members were typically expected to help pay for care. However, in several cases, they were unwilling to do so. Matthews and Rosner (1988) indicated that not all families are able to work together to provide parent care. Additionally, Piercy (2007) noted that the nuclear families of primary caregivers are more likely to be involved in the day-to-day care issues of elderly parents than are the siblings of primary caregivers. Furthermore, the case study presented in the findings section also demonstrates that even when the siblings in a family agree to collaborate for care financing, they may first need the intervention of an outside party to whom they are willing to listen, like a doctor or therapist.

Caregivers in this study also indicated that there were several obstacles to helping to pay for the care of an elderly parent. These age-related obstacles include issues like poor health and associated medical bills, paying for college age children's tuition, and not having enough income to save for retirement and pay for the long-term care costs of parents. Indeed, researchers have indicated that the increased longevity of elderly adults and their older adult children may be difficult as these children are anxious about their own retirement and health problems (Cicirelli, 1984). Research on caregivers in many age brackets is necessary to discuss whether caregivers of all ages experience personal obstacles in funding long-term parent care.

In addition to age related personal obstacles, caregivers today and in the next few decades may be facing increased inability to pay for long-term care. The current economic recession has left many elderly adults nearing retirement age with high losses in their retirement savings (Newman, 2009). This will have an impact on their ability to

pay for their own or their parents' long-term care. Similarly, the economic status of the United States and other countries has led to high numbers of job losses (Uchitelle, Grynbaum, & Myers, 2008). With higher unemployment rates, many middle-aged adults may face difficulty in paying for their parents or their own long-term care in the future.

Unnecessary to pay for long-term care. In this study, nearly half of the caregivers indicated that their parents were able to pay for part or all of their own long-term care costs. Because of this, and use of government-supported programs, only three of the thirty caregivers were required at the time of this study to help pay for long-term parent care. This finding is important because, although not all of the care recipients were paying for their own long-term care, almost half were able to pay for part of their own care. However, if current programs do not plan for an ever increasing population of elderly adults, more and more of these elders will need to plan for their own long-term care financing.

Family relationships. Throughout the interviews participants often referenced their own siblings and other family members in relation to caregiving situations. However, none of the participants directly stated that these various relationships were the reason that they were willing to pay for care. Instead, these relationships seem to be an indirect influence on the willingness of caregivers to fund parent care. Future research should be conducted with the siblings of primary caregivers to further identify the influence of family relationships on the willingness of caregivers to pay for long-term parent care.

Theoretical Framework

Ecological theory was used as the theoretical framework for this study. The ecological model developed by Urie Bronfenbrenner consists of multiple levels of interacting systems: micro-, meso-, exo-, and macrosystems (Bubolz & Sontag, 1993; Chibucos & Leite, 2005; Sontag, 1996). Figure 1 better illustrates the relationships between these systems, as applied to the systems that are the focus of this study.

Microsystem

The microsystem of long-term care is the smallest system in the ecological framework. In this study, the attitudes and moral beliefs surrounding long-term care of

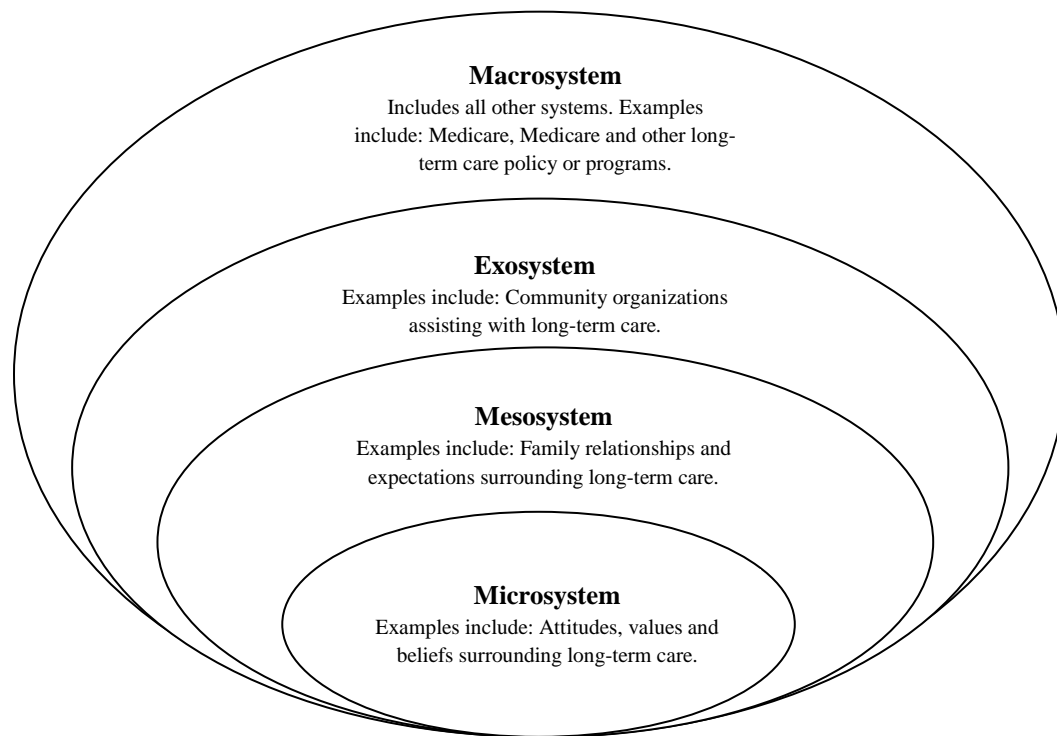


Figure 1. Ecological systems of long-term care.

individual caregivers represent the microsystem. This system can be influenced by religion and culture. The caregivers in this study were primarily members of the LDS church. Members of the church believe that families are responsible for taking care of one another. This belief about provision of long-term care had an influence on the way that many caregivers in this study felt about paying for long-term care. Similarly, culture can play a role in influencing the attitudes and beliefs surrounding long-term care. For example, African Americans have been found to be more likely to care for elderly parents at home than place them in a nursing home (Mbanaso, Shavelson, & Ukawuilulu, 2006).

Mesosystem

In contrast to the microsystem, the mesosystem is made up of various family relationships and expectations (e.g., sibling relationships, caregiver-care recipient relationships). In this study, many caregivers indicated that they were willing to pay for long-term care because of various family attitudes, responsibilities, and expectations. For example, several caregivers noted that they were willing to pay for care in the home because their parent had a high aversion to nursing home care. This family attitude, or aversion to nursing home care influenced caregivers' decisions to pay for long-term care in the home. Attitudes like these fall into the mesosystem of long-term care.

Exosystem

The exosystem of long-term care is the second to largest system of the ecological framework. This exosystem is made up of community organizations that aide caregivers in funding care, as well as caregiver friendly workplaces, hospitals, and organizations. In this study there were several community organizations, like United Way, Senior Centers,

or Area Agencies on Aging that were willing to provide caregivers with supplies, personal grants, or volunteers. These organizations impacted the ability of some caregivers to keep their parents in the home.

Macrosystem

The micro-, meso- and exo-systems together help to make up the macro system. Besides these included systems, the macrosystem also includes large overarching elements that influence lower systems. Programs like Medicare, Medicaid, and other state programs are components of the macro-system. For many caregivers in this study, the ability of their parents to qualify for Medicare or Medicaid-funded programs allowed them to stay in the home for long-term care and influenced the necessity of paying for long-term parent care. In addition, if changes in the macrosystem occurred, such as changes in the availability of Medicare or Medicaid, all systems of the ecological framework would be affected. For example, if Medicaid funding policies changed, causing a lack of funding for in-home care services, many caregivers would try to continue in-home care services by doing tasks themselves. They also might depend on local organizations more for help with services. These extra burdens on caregivers might result in over-burdening and stress. In turn this stress is likely to influence the family relationships and attitudes of the caregiver towards long-term care. High caregiver stress has been linked to earlier institutionalization for care recipients (Gaugler, Kane, Kane, & Newcomer, 2006).

System Interactions

Although each of these systems has a direct influence on the willingness and

ability of caregivers to finance long-term care, all of the systems work together. The microsystem, or attitudes and beliefs of caregivers towards long-term care, may impact how caregivers feel about utilizing Medicaid, Medicare, or local community and state organizations to provide care for an elderly relative. Similarly, mesosystem elements such as family expectations may help explain why caregivers pay for care themselves even when other funding possibilities like Medicare are available.

On the other hand, macrosystem elements like Medicare policies influence whether or not caregivers are able to pay for part or all of the required care for their parent. Organizations that donate volunteers or supplies to caregivers also influence the ability of caregivers to pay for long-term parent care. While the exo- and macrosystems can influence the ability of caregivers to pay for care, the microsystem and mesosystem are thought to have a larger impact on the willingness of caregivers to pay for care. However, as caregivers use and learn about macrosystem policies and programs, their level of satisfaction with providers of these macrosystem elements may influence their utilization of available services.

Policy Implications

Health care reform has long been a policy debate. Similarly, long-term care financing is a policy problem that has not been solved. The findings from this study have the potential to inform policy makers as they try to find the best solutions to these problems. Perhaps one of the findings with the largest policy implications from this study is that there are family caregivers who are willing to do what they can to help fund long-term parent care. In addition, although willing, many of these same caregivers viewed

themselves as unable to pay for this long-term care.

Policy makers addressing these findings may consider ways to support family caregivers in their efforts to provide long-term care financing. This could be done in several ways that might include larger tax breaks for caregivers who fund long-term parent care and the expansion of more affordable home- and community-based programs. By making policy changes like these, policy makers will impact the ability of caregivers to pay for both their parents' and their own long-term care. This may be especially important in future years. Many middle-aged and older adults have lost their jobs in the current economic recession. This likely impacts their ability to save for long-term care costs. In addition, if policy makers do not do more to support families in their efforts to provide long-term care, many care recipients may end up utilizing more expensive, government funded nursing home care instead of home- and community-based care.

The fact that almost half of the care recipients in this study were able to pay for part of their own long-term care is another finding from this study with the potential to inform long-term care policy. Those care recipients who paid for their own long-term care costs often relieved their adult caregiver children of any potential financial strain. To address this finding, policy makers may consider greater incentives to elderly adults to pay for their own long-term care. Long-term care policy that features tax-advantaged long-term care savings accounts may encourage individuals and families to save for the high expense of long-term care (O'Shaughnessy et al., 2002). This is important because more and more adults will need long-term care in upcoming years (Friedemann et al., 2004). Encouraging savings for long-term care will help to ease the use of governmental

programs funded with taxpayer dollars.

Another way that policy makers can help to alleviate the high costs of long-term care for individuals and families is to encourage a greater use of long-term care insurance. Currently, most long-term care insurance policies meet the federal standards for tax deduction (Kassner, 2007). However, as exemplified by this study, many older adults do not purchase long-term care insurance because it is often expensive and confusing. Greater efforts by the government to expand the use of long-term care insurance policies may encourage elderly adults to insure themselves. This may be done through policy that allows taxpayers to deduct insurance premium costs on their taxes (O'Shaughnessy et al., 2002).

Lastly, many caregivers and their adult children had a high aversion to nursing homes. This high aversion was a reason for many caregivers' willingness to pay for long-term care costs in the home. Because of these preferences, and the cost difference between nursing home care and home- and community-based long-term care, policy makers should implement policy that places a greater emphasis on use of home- and community-based care. A greater shift towards this type of care has been initiated with Medicaid home- and community-based long-term care waivers (Kaye et al., 2009; O'Shaughnessy et al., 2002; Palley, 2003; Stone, 2006). However, as discussed above, more can be done to encourage families to use home- and community-based long-term care.

Limitations and Suggestions for Future Research

The majority of the participants in this study were similar in age, culture, and

religious preference. In addition, participants were not randomly selected. Due to this nonrandom selection, and the homogeneity of the participants in this sample, the results of this study cannot be generalized to family caregivers in all cultural or religious settings. More specifically, because the participants in this study were primarily Caucasian and members of The Church of Jesus Christ of Latter-day Saints (LDS), more work needs to be conducted with other religious and cultural groups. Future researchers wishing to generalize similar data should seek for random sample with more heterogeneity.

The categories of willing, unable, and unnecessary to pay for care arose in the analysis of this study. None of the participants in this study indicated that they were unwilling or ambivalent when it came to paying for long-term care. However, the general population of caregivers may include those who are unwilling or ambivalent in their attitudes about long-term care financing. Due to the data collection process (interviews) of this study, those with ambivalent or unwilling attitudes may not have felt comfortable displaying such attitudes to interviewers. Future researchers may choose other data collection methods that may help to decipher the extent to which such attitudes are present among various samples of family caregivers.

Caregivers in this study noted that their siblings were a contributing factor to their inability to pay for long-term care. Although family members indicated that their siblings would, or wouldn't help pay for care, future research may involve interviews with siblings and other members of the care recipient's immediate family. By interviewing all members of the care recipients' family, researchers may be able to determine whether and

to what extent these care relationships and conflicts actually exist.

Although researcher bias exists in all forms of research, qualitative data is much more prone to be influenced by this bias. There were five interviewers in this study, all of whom were likely to introduce some bias into the data because of the social nature of the interactions with participants. Varied techniques of the five interviewers may also have had some influence on the consistency of the data. However, interviewers sought to minimize researcher bias and influence on the data by following the interview protocol and maintaining professional interpersonal boundaries with the participants.

Conclusions

Advances in medicine and large numbers of aging baby boomers have created a situation in which more elderly adults than ever before will need long-term care in future years (Friedemann et al., 2004; U.S. Census Bureau, 2000). As they age, these baby boomers will find that long-term care is expensive. However, a recent shift towards, and preferences for home-based long-term care (Bishop, 1999) help to alleviate the high costs of nursing home care for elderly adults and their family members (O'Shaughnessy et al., 2002).

Presently, governmental programs aid families of elderly adults in paying for long-term care via programs like Medicare and Medicaid (Stone, 2006). The current study helps provide an understanding of the attitudes and actions of family caregivers concerning long-term care financing. Findings from this study suggest that there is much variability in the willingness and ability of caregivers to pay for long-term parent care. However, caregivers in this study were typically willing yet unable to help pay for long-

term parent care in the home. Based on these findings, it is suggested that policy makers enact policy that will encourage and help family members and elderly adults to pay for long-term care. Doing so may alleviate the burden of long-term care for elderly adults and their families. Additionally, governmental support for home-based long-term care may ease the use of costly nursing home care, costing the government and taxpayers less.

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APPENDICES

Appendix A:
IRB Approval Letter

UtahState UNIVERSITY

INSTITUTIONAL REVIEW BOARD OFFICE
 9539 Old Main Hill, Suite 214a
 Logan, UT 84322-9530
 Telephone: (435) 797-1821
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USU Assurance: FWA#00003308
 Protocol # 2370

SPO #:
 AES #: UTA00

6/26/2009

MEMORANDUM

TO: Kathy Piercy
 Patricia Davis

FROM: Kim Corbin-Lewis, IRB Chair *Kim Corbin-Lewis*
 True M. Fox, IRB Administrator *True M. Fox*

SUBJECT: Financing Home and Community-based Long Term Care: Adult Children
 Caregiver

Your proposal has been reviewed by the Institutional Review Board and is approved under exemption #4.

- There is no more than minimal risk to the subjects.
 There is greater than minimal risk to the subjects.

This approval applies only to the proposal currently on file. Any change in the methods/objectives of the research affecting human subjects must be approved by the IRB prior to implementation. Injuries or any unanticipated problems involving risk to subjects or to others must be reported immediately to the IRB Office (797-1821).

The research activities listed below are exempt based on the Department of Health and Human Services (DHHS) regulations for the protection of human research subjects, 45 CFR Part 46, as amended to include provisions of the Federal Policy for the Protection of Human Subjects, June 18, 1991.

4. Research, involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

Appendix B:
Interview Questions

First Interview

General Caregiving

1. Tell me what led to your providing help to your parent. How long have you been providing assistance to your parent? How were decisions regarding current caregiving arrangements made?
2. What are your current caregiving arrangements? Are there any other family members or friends who help you provide assistance to your parent? If so, what do they do?

Choices for Long-term Care

1. Other than the services of the home care provider you are receiving now, what choices for outside help do you have?
2. Are you aware of other home care or community programs for which your relative may qualify? What are they?
3. How willing would you be to consider using one of these services?
4. How willing would you be to take financial responsibility for these services?
5. What would happen if you were no longer able to provide or oversee care? How would a new arrangement be made? Who would be involved in the decision-making process? What factors would influence the decisions made?

Home Care

1. What have been your experiences with the home care services you are using?
2. What have been your experiences with their regulations and payment system?
3. Do you have any concerns for the future regarding home care services or payment for them?

Second Interview

Relationship and Economic Issues

1. How has caregiving affected the various aspects of your life?
Your relationship with your parent? Parent-in-law?

Your relationship with other family members?

Your relationship with your spouse?
2. How would you like to be better supported in your caregiving efforts?
3. How has your family financial situation affected decisions about how to provide care for your parent? Parent-in-law?
4. Is your parent able to pay for home care assistance from his or her funds? For how long?
5. Would you consider paying for home care services for your parent? Why or why not?
6. In your opinion, whose responsibility is it to pay for parent care in the home setting? What are the reasons that you feel this way?

Wrap Up

1. Based on your experiences with long-term parent care at home, what do you see as the most pressing issues for those who care for parents at home?
2. How have your experiences with parent care affected your ideas and plans for your old age?
3. Have you talked with your children or other family members about how you would like to be cared for?

Thank you for your answers and input into these important issues.

Appendix C:
Demographic Questionnaire

Financing Home-Based Long-term Care: Family Caregiver Perspectives

Questionnaire

It is important to us to understand your background as much as possible. Below are several questions for you to answer that will give us this important information. Please let me know if anything asked here is unclear to you.

Today's Date: _____

Place: _____

Interviewer's Name: _____

The following questions are about you:

Your Name: _____

Gender (check one): Female _____ Male _____

Date of Birth: _____

Birth Place: _____

Birth Order in your family: 1st__ 2nd__ 3rd__ 4th__ 5th__ 6th__

Brothers: (city & state)

Name: _____ present age _____ lives in _____

Name: _____ present age _____ lives in _____

Name: _____ present age _____ lives in _____

Sisters:

Name: _____ present age _____ lives in _____

Name: _____ present age _____ lives in _____

Name: _____ present age _____ lives in _____

Your Education

highest grade completed _____ (give the number)

College Graduate Yes No (check which applies)

Post-graduate degree Yes No (check which applies)

Type of post-graduate degree (specify) _____

Occupation

Your Present Occupation: _____

Number of hours worked per week in current occupation: _____

Retired Yes No

If retired, number of years retired _____

Marital Status (check one):

married

separated

divorced

widowed

single, never married

Children:

answer

(yes or no)

name: _____ age ____ gender ____ living at home ____

name: _____ age ____ gender ____ living at home ____

name: _____ age ____ gender ____ living at home ____

name: _____ age ____ gender ____ living at home ____

Religious preference (list denomination; if no preference, leave blank)

For the next two questions, **check** the answer that best describes you today.

Quite apart from attending religious services, how important would you say religion or spirituality is to you?

- very important
- somewhat important
- not important

How would you describe your financial resources (money to live on) at the present time?

- much less than adequate
- less than adequate
- adequate
- more than adequate
- much more than adequate

What is your **current annual income** before taxes? (Circle the number that applies)

Your Individual Income		Total Family Income	
1	Less than \$10,000	1	Less than \$10,000
2	\$10,000 - \$19,999	2	\$10,000 - \$19,999
3	\$20,000 - \$29,999	3	\$20,000 - \$29,999
4	\$30,000 - \$39,999	4	\$30,000 - \$39,999
5	\$40,000 - \$49,999	5	\$40,000 - \$49,999
6	\$50,000 or more	6	\$50,000 or more

The following questions pertain to the person for whom you are caring.

Care Recipient's Name _____

Care Recipient's Gender Male Female

Relationship to Care Recipient: _____ (please specify type of relationship, such as daughter, friend, daughter-in-law, etc.)

Care Recipient's current age _____

What funding source is paying for care recipient's home care? (check ones that apply)

- Medicare
 Medicaid
 State funds (Alternatives program)
 Personal funds Care Recipient's Caregivers Both
 Insurance policy
 Other (please specify) _____

Is Care Recipient on Medicaid? Yes No

What is care recipient's current annual income before taxes? (Circle the number that applies)

- 1 Less than \$10,000
2 \$10,000 - \$19,999
3 \$20,000 - \$29,999
4 \$30,000 - \$39,999
5 \$40,000 - \$49,999
6 \$50,000 or more

Please estimate the worth of the care recipient's assets at the present time (in dollars):

Thank you very much for your responses.