Dementia Cregiving in the United States: Implications for Long-term Care

Rashmita Basu and Robert Rosenman

Basu: rashmita_basu@wsu.edu PhD candidate, School of Economic Sciences, Washington State University, Pullman, WA 99164-6210
Rosenman: yamaka@wsu.edu Professor, School of Economic Sciences, Washington State University, Pullman, WA 99164-6210

Abstract.

Informal care is an important source of long-term care (LTC) for persons with dementia and cognitive impairments. Using the Aging Demographic and Memory Study (ADAMS) dataset this study analyzes a sequence of *predisposing*, *enabling* and *need* factors that jointly predict the amount of informal and formal health care received by individuals with dementia in the US. The 'altruistic' motivation to provide care increases the level of informal care and delays the institutionalization. Caregivers' physical, emotional stress and change in perceived health status associated with caregiving increase the use of formal home health care services. The need for supervision to protect the consequences of impaired judgment significantly increases the amount of both informal care and formal home health care. The findings have profound social and health implications for expanding the publicly funded LTC needs for individuals with dementia to capture the unique nature of the disease.

JEL classification: I12; J14; J22.

Keywords: Informal care, Long-term care, Formal health care utilizations, Dementia and CIND.

1. *Introduction*

The most dramatic change in the structure of the US population over the last quarter century is the growing number of older persons in the population, both in the absolute numbers and the percentage in the total population (CDC, 2003). According to the 2000 Census estimates, the elderly population (aged 65 and older) is expected to double: from about 35 million to more than 70 million by 2030. The aging of the US population has raised significant interest among researchers and policy makers in designing efficient and effective system for delivering health care needs (especially, long-term health care) to the older people. With the aging of the population, long-term health care of elderly becomes an important and increasingly larger element of the country's health care system.

With the rising number of elderly in the US population there is a marked increase in the prevalence and incidence of dementia and other neurodegenerative diseases[1]. The most common type of dementia is Alzheimer's disease (AD), a progressive, debilitating and irreversible neurodegenerative disease. AD accounts for 60 to 80 percent of all dementia cases (Alzheimer's Association: Facts and Figure, 2008). According to the Aging Demographic and Memory Study (ADAMS) the prevalence of dementia among

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[1] Dementia is defined as acquired deterioration of memory and cognitive functions that impairs a person's ability to perform independent function of daily living (Harrison, 16th edition). These functional limitations impose substantial burden on individuals, families and health care system. Cognitive Impairment Not Demented (CIND) is a transitional state between normal aging and dementia (Larrieu et al.; 2002). There is a prodormal phase during which individual's daily normal activities are impaired, yet the changes in cognition are insufficient to classify as dementia. But studies have shown that persons with CIND are at an increased risk of developing AD in future (Yuek at al; 2008, Yuek et al; 2006). The Cardiovascular Health Study of Cognition estimates CIND prevalence rate of 22% among individuals of age 75 and above (Lopez et al., 2003).

individuals aged 71 and above was 13.9% and the corresponding number for Alzheimer's disease was 9.7% in 2002 (Langa et al.; 2002).

Most people with dementia live at home, with informal help from family and friends. The primary informal caregiver[2] is responsible for day-to-day decision making and provision of care to the individuals with dementia (Herbert et al., 2001). Understanding the factors that determine the use of formal health care services and the provision of informal care is important for predicting the use and formulating long-term care policy. Using the Aging Demographic and Memory Study (ADAMS) dataset this study analyzes a framework for understanding a sequence of *predisposing*, *enabling* and *need* factors that influence the joint decision of informal and formal health care utilizations of individuals with dementia in the US.

Informal caregivers spend significant amounts of time providing care for individuals with dementia and cognitive impairments due to progressive functional limitations and loss of independent functions (Langa et al., 2002). In 2007, 9.8 million unpaid caregivers provide care for people with AD and other types of dementias (ALZ Association: Facts and Figures, 2008). Economic value of this unpaid care was estimated as $89 billion in 2007. As the prevalence of AD, increases exponentially[3], scope of informal care and its importance to the society and health care system will continue to increase the surge of interest of researchers and policy makers alike.

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[2] The primary informal caregiver is defined as anybody who is mostly responsible to provide unpaid help (other than some form of caregiving satisfaction) for the care recipient within a social environment simply because the care recipient is unable to perform daily activities because of inability to perform independent functions.

[3] By 2050, the number of individuals age 65 and older with AD would approximately be 14 million, compared to 4.5 million in 2000(Hebert et al., 2003).

People with dementia have higher frequency of using formal health care services than normal Medicare beneficiaries and it costs Medicare approximately 3 times higher than normal beneficiaries (ALZ Association: Facts and Figure, 2008). Family members who provide the bulk of care for impaired elders are likely to determine the elder's use of formal health care services (Bass & Noelkar, 1987). Therefore, the decision on the use of both cares, often times, is made jointly.

2. *Literature Review*

The conceptual framework developed by Anderson (Anderson and Aday 1978) explains how the individual determinants influence different types of formal care utilizations. But Anderson's model shows a lack of attention to the importance of informal care services for the older people. The conceptual expansion of Anderson framework was extended by Bass and Noelkar (1987) by including *predisposing*, *enabling* and *need* characteristics of both primary caregivers and elder care recipient. But this study focuses on only formal in home services and ignores the use nursing home care, another form of long term care service.

Studies in literature provide mixed evidence of relationship between informal support by family member and the use of formal care services for the older persons. This suggests that there are important gaps in understanding how these two cares influence each other. One of the important factors in understanding this relationship is to understand individual determinants that influence the joint decision of these two cares. Studies in the literature (Bolin et al. 2008; Van Houtven & Norton 2004; Charles & Sevak 2005,Lo Sasso and Johnson, 2002) explaining the relationship between informal and formal care examine patient's optimal decision problem in determining the level of formal care use assuming a fixed level of informal care supplied by adult children. Most of these studies ignore the influence of caregiver level characteristics on the choice of formal care and consider only the patient level characteristics. But caregiver level determinants certainly have influences in predicting both the cares when the decision is made by a caregiver. This is especially true for individuals with dementia because of lack of using proper judgments in decision making (Gauler et al.; 2000).

Some other studies (Langa et al., 2001; Liu et al., 2004) found that higher paid home care between 1993 and 1995 was associated with people with greater social support and change in home health care policy had shifted distribution of paid care services towards elderly living with their children. On the other hand Van Houtven & Norton (2004) and Bolin et al. (2008) found that informal care is a substitute to nursing home entry and formal home health care services.

The caring for a person with dementia is very stressful and demanding (Bedard et al., 2000; Zweifel & Konig 2004, Schulz & Martire, 2004). Relatively little is known about caregiving decisions and experiences about providing care to a person with dementia. One such issue is the simultaneous choice of both informal and formal care services in caregiver's optimal decision problem. Moreover most studies restrict informal care to adult children only, while significant proportion of informal care is provided by spouse or other family members or friends[4]. There is evidence that adult children play dominant role in the care of disabled women whereas wives play important role in the care of disabled men (Langa et al., 2000). Additionally, dementia caregivers are more likely than nondementia caregivers to be spouse vs. adult children (7.2% vs 3.1 % spouses;

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[4] Family Caregiver Alliance, 2000 reports more than 50% informal caregivers are spouse or other family members or friends.

48.9% vs. 52.8% adult children, R.Schulz (Ed), 2000). Therefore restricting informal caregiving only to adult children may not truly uncover the effect of the caregiver level determinants on both cares.

This study extends the caregiving literature by examining the provision of informal care by spouse, adult children or other family member, the simultaneous choice of informal and formal care, and the implication of patient and caregiver level characteristics in formulating long-term care policy for ensuring better and effective health care needs for individuals with dementia.

3. Conceptual Model

The conceptual model of caregiving focuses on how an informal caregiver makes the optimal decision of choosing the use of formal health care services and the provision of informal care. The crucial assumption of the altruistic motive is that a caregiver weights patient's well-being (patient's health status) in measuring her/his satisfaction from the caregiving process (Wolf et al., 2001).

It is important to understand the factors that influence decision to become an informal caregiver. One such factor is obviously the incidence of illness in caregiver's direct social environment. Often, caregivers take the decision to combine both formal and informal care. Both formal and informal cares provide utility to a potential caregiver (Brouwer 1999). When an individual decides to become an informal caregiver, from the revealed preference viewpoint, it is clear that this is a constrained utility maximizing decision, otherwise the caregiver would have chosen alternatives to informal care (formal care, paid home health care etc). Providing informal care yields utility to a caregiver through the patient's health status.

The caregiver determines optimal amount of the informal care, t_{ic} to provide, to maximize utility,

$$U = [U^{ic}\{(C, t_l, h^p(t_{ic}, F)) + \gamma * t_{ic}\}] \qquad (1)$$

An informal caregiver optimizes the utility by choosing informal care hour t_{ic}, hours spent on leisure, t_l and amount of formal care, F. It is realistic to assume that caregivers desire improvement in patients' health status, h^p (h^p is a function of t_{ic} and F); hence patient health status is always incorporated into the utility function. But an altruistic caregiver certainly enjoys providing informal care. This is reflected by including the additive term $\gamma*t_{ic}$ in the utility function. The functions U^{ic} and patient's health (h^p) are strictly concave functions with positive first partial derivatives and negative second partial derivatives with respective arguments. The parameter γ shows the weight of patients' utility relative to caregiver's utility which indicates the degree of altruism[5] of a caregiver to a patient. The parameter γ is assumed to be either positive or zero. If γ =1, then the caregiver is altruistic and the degree of altruism is reflected by a shift in the t_{ic} function. Whereas, γ=0, the caregiver is not altruistic but provide the minimum amount of care either due to legal obligation or personal morality or filial responsibility. In this model, all decisions are made by the caregiver and the ill person is considered as passive recipient of caregiver's care. All the available funds, partly, earned by labor income and partly other (nonlabor) net income y_0 are spent on formal care and consumption, therefore, the budget constraint is

$$C + p_f F = wt_p + y_0 \qquad (2)$$

Total time is restricted as:

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[5] In this study altruism is defined as when a caregiver's utility increases if the caring role improves a patient's wellbeing (Becker, 1981).

$$T = t_p + t_l + t_{ic} \qquad (3)$$

Where T is the total time spent on informal caregiving (t_{ic}), leisure (t_l) and paid work (t_p).

Equations (2) and (3) can be combined to get the total income constraint as

$$C + p_f F = w(T - t_{ic} - t_l) + y_0 \qquad (4)$$

In equation (4) y_0 is the net nonlabor income, w is the market wage rate, p_f is the price of formal care, F is the amount of formal care purchased and C is the numeraire consumption good. The right hand side of (4) is the total income (nonlabor plus labor) of a representative caregiver and the left hand side is the total expenditure spent on consumption and formal care. The amount of informal care (t_{ic}) and formal care (F) services depend on p*redisposing*, e*nabling* and *need* characteristics of a patient and a caregiver.

The Lagrange function for this optimization is as follows;

$$\text{L}=[U^{ic}\{(C, t_l, h^p(t_{ic}, F)) + \gamma * t_{ic}\}] + \lambda[p_f F + C + w(t_{ic} + t_l) - wT - y_0] \qquad (5)$$

To solve the above optimization problem derive the first order conditions for maximizations and setting them equal to zero yields

$$L_{t_{ic}} = \left(\frac{\partial U^{ic}}{\partial h^p}\frac{\partial h^p}{\partial t_{ic}}\right) + \gamma + \lambda w = 0 \qquad (6)$$

$$L_F = \left(\frac{\partial U^{ic}}{\partial h^p}\frac{\partial h^p}{\partial F}\right) + \lambda p_f = 0 \qquad (7)$$

$$L_{t_l} = \frac{\partial U^{ic}}{\partial t_l} + \lambda w = 0 \qquad (8)$$

$$L_\lambda = p_f F + C + wt_{ic} + wt_l - wT - y_o = 0 \qquad (9)$$

Combining the marginal conditions (6) and (7) we derive

$$\frac{\frac{\partial U^{ic}}{\partial h^{p}}\frac{\partial h^{p}}{\partial t_{ic}}+\gamma}{\frac{\partial U^{ic}}{\partial h^{p}}\frac{\partial h^{p}}{\partial F}}=\frac{w}{p_{f}} \qquad (10).$$

Rearranging,

$$\gamma=[\frac{w}{p_{f}}(\frac{\partial U^{ic}}{\partial h^{p}}\frac{\partial h^{p}}{\partial F})-(\frac{\partial U^{ic}}{\partial h^{p}}\frac{\partial h^{p}}{\partial t_{ic}})] \qquad (11)$$

The equation (11) implies that the optimal choice of t_{ic} and F will depend on γ. In this model the caregiver is making the endogenous decision on the optimal levels of t_{ic} and F. The optimal levels of t_{ic} and F can be determined as

$$t_{ic}^{*}=f(w,y_{0},\gamma,p_{f},X,Z) \qquad (12)$$

and

$$F^{*}=f(w,y_{0},\gamma,p_{f},X,Z) \qquad (13)$$

Where w is the wage rate of a working caregiver, y_0 is non labor income represented by the family wealth, p_f is the price of formal care, γ is the altruistic parameter and finally X and Z are the vector of *predisposing*, *enabling* and *need* factors of both the impaired person and the caregiver. In the empirical model, due to missing data on hourly wage rate, caregiver's annual earning is considered as a proxy of wage rate. Also, the empirical analysis uses proxy indicators of availability of formal care (for example, having Medicaid) for the price of formal care (Kemper 1992).

4. Factors Determining Informal and Formal Care Utilizations.

The sequence of factors that may affect both the receipt of informal care and as well as the use of formal care utilization, includes *predisposing*, *enabling* and *need* factors of both the impaired person and the caregiver. The use of health care services is dependent on, first, the predisposition of the individual as suggested by demographic and social characteristics and beliefs about health services. These factors are known as *predisposing* variables. Secondly, ability to access to those services depends on own personal resources and availability of health services. These are known as *enabling* variables and finally person's state of illness determines the *need* variables.

The *predisposing* variables include socio-demographic characteristics and health related attitudes that predict the use of formal care services as well as informal care (Anderson & Aday; 1978, Bass & Noelker, 1987). These factors are age, gender, race, and beliefs about the health care utilizations. It can be expected that married people would be more likely to receive informal care from their spouses or other family members that enable them to remain in home or community. (Lo Sosso & Jonson, 2002). Moreover demographic variables such as age, gender indicate well-established relationship with illness patterns (Anderson & Aday, 1978).

Typically, one family member is responsible for providing care to the elder person (Townsend & Poulshock 1986). This primary caregiver is most often a spouse or an adult child (Bass 1985). Because of single person's responsibility in caring the elder person, research on caregiving has uncovered negative consequences of caregiving directly associated with caregiver's relationship with the elder person. For example spouse caregivers report high levels of physical and emotional strains in addition to financial burdens (Bass & Noelkar, 1986). On the other hand adult caregivers express familial conflicts especially when married with dependent children (Brody 1981, Bass & Noelkar, 1986).

The *enabling* factors include the characteristics of care recipient and caregiver that refer to the resources that promote or inhibit the access to use the services. Often some of these factors are found to be common for the impaired person and the caregiver. One of the important *enabling* factors is identified by the availability of immediate family members. The empirical analysis uses whether the person is married or not and has children or not as an indicator of the availability of family. Another important factor is whether a caregiver lives in the same household with the patient as it influences the level of informal care as well as the use of formal health care services (Greene 1983, Bass & Noelkar 1986). The living arrangement decision may be endogenous to the caregiving decision if a caregiver jointly determines the amount of formal and informal care used and living arrangement. In this study I assume that a caregiver determines the optimal amount of formal and informal care used conditioned on whether she/he lives in the same household with the patient or not (Greene1983). In other words, there are no such factors that affect one also affect the other. There are other *enabling* factors those are unique to the patient and the caregiver. For example caregiver's education level which can be a proxy for knowledge of services, whereas a patient's education level influences formal service use. In the empirical analysis only a caregiver's education level is considered as an *enabling* factor, as she/he is a single decision maker.

The final set of *enabling* factors include price of formal care, family wealth and caregiver's income level that affect the access to formal care services. For example, higher price of formal home care is expected to decrease use of home care services and increase use of informal care. Because of lack of data on the price of formal care services, it is not possible to test the hypothesis. In empirical analysis, I use the availability of Medicaid as a proxy for price (Kemper, 1992). But having Medicaid will not capture the price for formal home care because Medicaid covers little on formal home health. Higher family wealth is expected to lead to use of more formal care-as it permits an informal caregiver to spend more time for activities other than caregiving (paid work or leisure)-use of less informal care. A Caregiver with higher income tends to use more formal care services.

At the patient level, the *need* factors are severity of illness or impairment (ADL, IADL) that necessitates the use of formal care services. It is reasonable to hypothesize that the amount of care required is positively correlated with the severity of a patient's impairments. Another important need factor expected to influence the amounts of informal and formal care is the need for supervision to protect the consequences of impaired judgment, fluctuation in decision making capacity, and impulsive, inappropriate or disruptive behaviors that is typical for a person with dementia. In the empirical model the variable indicating 'need for personal safety' is considered as a proxy for this factor. On the contrary, caregiver level need factors include physical and emotional stress or strain associated with caregiving, activity restrictions, a change in perceived health status resulting directly from the caregiving responsibility. The stressful effects of caregiving are exacerbated when the elder person is cognitively impaired, emotionally disturbed, incontinent and immobile and has multiple and severe functional limitations (Noelkar 1984). These negative consequences may increase the need for formal health care services. The information on health care utilization, receipt of informal care and socio-demographic characteristics are described in table 1.

5. Data Description

This study uses data from The Aging Demographics and Memory Study (ADAMS), conducted by Health and Retirement Survey (HRS), with specific aim of collecting data from population-based survey on dementia among older Americans. ADAMS provides a unique opportunity for conducting in-depth investigation about the impact of dementia on formal health care, informal caregiving and relationship between these two cares. It includes subjects from all regions of the country, using a standardized diagnostic protocol.

The ADAMS sample starts with stratified random subsample of 1770 respondents aged 70 and above at the time of selection from HRS sample. The sample is composed of five cognitive strata from “low functioning” to “high normal” based on self or proxy cognitive measures in their most recent HRS interview (2000). To ensure a sufficient number of respondents across the full range of cognitive abilities, the 3 highest cognitive strata are further stratified by age and sex. ADAMS initial assessment, phase-I was completed on 856 respondents (56% of nondeceased target sample) between August 2001 and December 2003. The ADAMS follow-up assessment, phase 2 between November 2002 and March 2005 was completed for 252 subjects for whom reassessment would be useful to know the severity of dementia. Full details of the ADAMS sample design and selection methods are described in other studies (Langa et al.; 2005, Plassman et al.; 2007). This study uses cross-sectional data from the first phase of the ADAMS, collected between August 2001 and December 2003.

The ADAMS provides extensive information on demographics, formal health care utilizations, informal caregiving including caregiver stress, strain caregiver depression, adjustments to work schedule due to caregiving responsibility and leisure time activities. It's linkage with HRS, provides detail information on health, health care utilization, economic resources and behavior allows investigation on in-depth analysis of factors influencing informal care and the use of formal health care services among the older US population. At the respondent level ADAMS provides information on health-related variables, self-reported health, number of limitations in ADL and IADL, use of formal health care utilization by type, medical insurance and patient's demographic characteristics. This database also includes detail information; economic variable such as current income and other demographic information

6. Method and Empirical Specification.

The theoretical model provides the foundation for the empirical specification and the estimation method. Both informal and formal cares are determined jointly based on a single optimizing decision by the caregiver, thus *Seemingly Unrelated Regression* or *SUR* would be the appropriate method of estimation. In any optimization problem, endogenous (choice) variables can be expressed in terms of exogenous variables and model parameters. If the optimization problem is not separable in terms of the choice variables, then the reduced form equations for those choice variables share the same set of exogenous variables. In this case the optimization problem is nonseparable in the choice of informal and formal care because of budget constraint and that indicates that the reduced-form model should have same set of regrssors[6]. The system of equations (12) and (13) can be rewritten as follows:

$$t_{ic} = \mu x' + \delta z' + \alpha w + u \qquad (14)$$

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[6] Three regressions are estimated for three types of formal care as: formal home health care, nursing home use and hospital use.

$$F = \beta x' + \varphi z' + \eta w + v \qquad (15)$$

The vectors x and z represent patient and caregiver level's *predisposing, enabling* and *need* characteristics that influence the levels of informal and formal care services. The variable 'w' in equations (14) and (15) is a binary indicator variable *whether providing care makes caregiver feels good*. This variable indicates caregiver's motivation to provide care as it makes the family caregiving different from help provided by formal services. This motivate may come from feelings of love and affection and desire to reciprocate for support provided earlier in life or filial responsibility.

6.1 Dependent Variables

Informal Care: The majority of informal care is provided because of functional limitations in Activity of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL) due to cognitive impairments. But additional care is also provided for supervision and transportation due to behavioral problems associated with dementia (Langa et al.; 2001). Because of this fact, informal care hour is considered as time spent on active care, supervision and transportation. Informal care hours are calculated by estimating number of hours a caregiver provided per month. The questions were asked as "*how many days in last month did you provide active care, supervision and transportation?*" and "*days you provide care, how many hours per day?*" Because of the skewed distribution of informal care hour, the log of total informal care hours provided per month[7] is considered as dependent variable. In the sample, 79 % of informal caregiver is primary caregiver. On an average 195 hours of informal care was provided per month for active care, supervision and transportation. Because some caregivers answered one but not both of the questions, a

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[7] I Consider log of (1+ informal care hours per month), and same for formal care utilizations as used in Bolin et al.; 2008, Van Houtven &Norton;2004, Sasso& Johnson; 2002.

bracketed variable is created for those missing cases (10) based on assumptions about the intensity of care-giving per day for dementia and impaired persons (Langa et al.; 2001). Based on national estimates of quantity of informal care for individuals with dementia, 27 hours per week or 4 hours per day was assigned for those 10 cases (Langa et al.; 2001). The analysis was re-run without those 10 cases and no significant change is found. Informal care hours are missing for 5% cases and Heckman (1979) model is used to examine sample selection bias and no evidence of sample selection bias is found due to missing observation of informal care hours.

Formal Care: Formal care utilization is measured by using three separate dependent variables-indicating amounts of formal care utilizations. The variables indicating amount of utilization are: the number of (1) nursing home stays and (2) hospital stays and (3) formal home health care (for example, specialized nursing care and other maintenance care). Dependent variables (nursing home use and hospital use) are logged in order to reduce the influence of skewed data on formal care utilizations numbers. On an average, number of nights in nursing home stay and hospital stay are 67 and 5. The number of formal home health care use is 1.35, on an average.

6.2 Independent variables

The patient level demographics include patient's age, gender, ethnic background and marital status. The average age of a patient is 85 years who had less than high school education. About 67% of respondents are married and 63% are female. Ethno-racial composition includes 69% Caucasians, 20 % African American and 11% Hispanic.

About 75 % of the sample members needed assistance with ADL and 90% needed help with IADL. Those who needed help, assisted with an average of 3.5 ADL and 4.2

IADL. Health insurance characteristics reflect the universal coverage by Medicare with 96 % of patients receiving Medicare and about 27% received Medicaid. About 25% received both Medicare and Medicaid. Only 5% has long term care insurance.

The average age of a typical caregiver is 61 years who had more than high school education and about 73 % caregivers are female. Caregiver composition includes 22% spouse, 51 % adult child and 27 % friends and other family members. About 40% caregivers worked for pay and average earning per year is $10,008. Caregiver's racial composition includes 65% Caucasians, 23% African American or others and 12 % Hispanic. About 50% caregivers live with the patient in same household. On an average caregiver reported having good health status, 68 % caregivers reported stress in caregiving process, 52% reported reduced level of physical exercise due to caregiving responsibility. All the summary statistics are reported in table 1.

<Insert Table 1 here>

7. Estimation, Results and Discussion.

As evident from equations (14) and (15) that both informal and formal care equations share the same set of regressors, thus there is no gain in efficiency of estimating them as a system (SUR) as opposed to estimating equation-by-equation using ordinary least squares (OLS). Table 2 describes the patient and caregiver level *predisposing, enabling* and *need* characteristics that jointly determine the level of informal and formal care by types of utilizations.

<Insert Table 2 here>

7.1 Predictive factors of informal care

Predisposing characteristics

At the patient level, higher age is associated with higher level of informal care as functional impairments increase with time. Married patients are more likely to receive higher informal care compared to single or never married. This confirms the fact that married people remain in community with informal help longer than single.

Among the caregiver characteristics, being female increases the level of informal care provision and this confirms the fact that majority of caregivers are female (73% of dementia caregivers are female, Schulz, 2000). The demand for informal caregivers will continue to increase in future years but the pool of middle-aged women who have traditionally provided care will be substantially smaller due to increased migration, increasingly fragmented families (Van Houtven and Norton 2008) and increased women's labor force participation (Juhn and Potter 2006) . This finding has an implication for formulating any intervention policy that can encourage and motivate family caregivers to provide informal care in order to increase the supply of informal care in future years.

As expected, a married caregiver tends to provide less care compared to a single or divorced or separated. This result is consistent with the fact that familial conflict or household disruption of married caregiver is an important predictive factor of informal care. Compared to the adult child and other family members, spouse caregiver provides less informal care, this may be because spouse caregivers report more often high level of physical and emotional stress in addition to financial burden. Compared to Caucasians, Hispanic and African American provide more informal care. The results are consistent with previous findings.

Enabling Characteristics

Living arrangement of both the patient and caregiver is one of the most important enabling characteristics that predicts the level of informal care. The result shows that living in the same household increases the level of informal care significantly. Another important enabling factor is the level of education. Compared to lower education, caregivers with higher education (some level of college education) provide less informal care. This result can be explained by more educated caregivers are able to provide less informal care because of time constraints (Van Houtven and Norton 2004) and also being able to better navigate support services (Bass and Noelkar, 1987). This is also because of higher opportunity cost of informal care for educated caregivers. Greater availability of immediate family, measured by whether the patients are married or not and have children, increase the use of informal care. Finally, higher wealth reduces the level of the informal care. These findings are consistent with the previous literature.

Need Characteristics

Among the patient's need characteristics the most significant predictor of informal care is need for supervision for patients' safety. The positive coefficient indicates that the need for supervision to protect the consequences of impaired judgments significantly increases the reliance on informal care. The higher number of limitations in both ADL and IADL impairments are more likely to receive more informal care. An increase in number of chronic conditions[8] increases the level of informal care.

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[8] Chronic conditions include problems with heart disease, lung disease, hypertension, diabetes, had ever stroke, cancer, major fall and hip fracture.

The variables used to measure caregiver need characteristics are activity restrictions due to caregiving responsibilities such as, schedule change at work place, give up work entirely, less time spent for leisure or hobby etc. The second indicator measures whether the caregiver perceives a change in physical health because of caregiving. This is measured by whether the caregiver reported reduced level of physical exercise, getting less sleep or rest due to caregiving responsibility. The third indicator is the measure of caregiving burden by considering the physical and emotional stress and strain associated with caregiving responsibility.

The activity restrictions (reducing leisure time, hobby time or schedule change) increases the level of informal support which intensifies the burden of caregiving. This indicates that family caregivers indeed make adjustments in their daily-life schedule to provide informal care to their family members. Physical stress associated with providing ADL or IADL significantly influence the level of informal care that also intensifies the burden of caregiving. The intervention policy should be targeted to reduce the burden of family caregivers by reducing the overall stress associated with caregiving responsibility. Deterioration of a caregiver's perceived health status decreases the informal care level, the result that has implication for higher use of the formal care services by both the patient and the caregiver. This is because one third of dementia caregivers are Medicare beneficiaries and negative effect on caregiver's health status is directly attributed to the higher Medicare or Medicaid expenditures for those caregivers. More importantly, caregiver burden is exacerbated due to overall stress and strain (both physical and emotional) associated with caregiving (as increase in stress does not reduce the level of informal care support) and this indicates the fact that primary caregiver experiences health related problems resulting directly from the caregiving responsibility. This uncovers the negative consequences of informal caregiving.

7.2 Predictive factors of formal health care services

Predisposing characteristics

Formal home health care and Nursing home care

At the patient level, higher age is associated with the higher use of formal home health care. Compared to single, married patients receive less formal care services of nursing home and more formal home health care services. This confirms that married people tend to leave in the community longer than unmarried or single that delays the institutionalization. Women significantly receive less formal long-term care than men. Reflecting findings from other studies (Van Houtven and Norton 2004, for example) Caucasians use higher formal health care services than African American. Among the caregiver level characteristics, an increase in caregiver's age significantly increases the use of nursing home stay.

Enabling characteristics

Among the enabling characteristics, living in a same household with the patient significantly reduces the intensity of both formal home health care and nursing home care. This result is consistent with previous finding that living with a caregiver reduces the use of formal home health care (Greene 1983). As expected, higher wealth is associated with greater intensity of formal long-term care use. Specifically, higher wealth level significantly increases the use of nursing home care. Having Medicare significantly increases the use of formal home care, on the other hand having Medicaid, significantly increases the use of nursing home stay, the result that has implication for higher expenditure of Medicare and Medicaid for long survivors. Availability of immediate family decreases the use of nursing home care but increases formal home health care.

Need characteristics

The most significant patient level predictor of formal home health care is the need for supervision for patient's personal safety. This finding actually corroborates one of the recommendations made by the Advisory Panel on Alzheimer's disease 1991, that the eligibility criteria to access publicly funded formal home care services for individuals with dementia should include the need for supervision rather than focusing only on the number of activity limitations in daily living. Higher number of functional limitations with ADL IADL performances increases the predicted level of both formal home health care and nursing home use. This is because informal help becomes difficult to perform when the patient has multiple or severe functional limitations, which is common for individuals with dementia or other cognitive impairments. Having higher number of chronic conditions, the use of formal home health care increases but nursing home use decreases.

Among the caregiver level need characteristics, change of caregiver perceived level of health decreases the use of formal home health care but increases the nursing home use. This effect is significant at 10% level. This result implies higher Medicaid expenditure for long survivors. An increase in caregiver's activity restrictions positively influences the use of formal home health care and nursing home use. Caregivers' physical and emotional stresses significantly increase the reliance on formal home health care. The burden of stress has negative influence on nursing home use, may be as nursing home care can be a substitute for home health care.

Hospital use

Predisposing factors:

Among the patient level characteristics, an increase in patient's age is associated with higher use of hospital stay. Again, female receives less formal care of hospital use. African Americans receive less hospital care than Whites. At the caregiver level, an increase in caregiver's age increases patient's use of hospital stays. Reflecting the same finding from other formal care services, having a female caregiver decreases the use of hospital stay.

Enabling factors:

Having Medicare increases the use of hospital stay. Living in a same household decreases the use of hospital care. Among the caregiver level characteristics, having college education decreases hospital use while, caregivers having positive earnings increase the use of hospital stay.

Need Factors:

The most significant predictor of nursing home use and hospital use is the number of functional limitations with ADL. The positive coefficient indicates that higher the number of limitations with ADL performance, higher will be the intensity of the use of both the formal care services. Higher number of chronic conditions is associated with higher use of hospital stay. This is due to the fact that coexistence of chronic conditions with dementia complicates the disease treatment and management and therefore requires specialized care. Compared to no smoking, current smoking/ smoking ever significantly increases the hospital use indicates that smoking increases the risks of other chronic illnesses that require specialized care.

Among the caregiver level characteristics, a change in caregiver's health status increases the use hospital stays, the result has implication for higher medical expenditures of Medicaid and Medicare for the health care needs of both the patients and the caregivers. Similarly, overall stress and strain associated with caregiving increases the use of both then formal care services.

Finally the effect of caregiver's motivation to provide care on informal care and formal health care services explains the role of altruistic motivation in predicting the demand for informal and formal health care services in future years. The positive coefficient on informal care indicates that if a caregiver is altruistic, the amount of informal care is increased after controlling for all other factors that may influence both. This result can also be explained by the caregivers' preference about delaying institutionalization of their loved ones. There is also evidence that the quality of family relationship, increased level of affection between caregiver and care recipient lower the institutionalization among dementia patients (Spitznagel et al. 2005). The positive effect on formal home care and negative effects on both nursing home care and hospital use strengthen the above result. An altruistic caregiver prefers to provide more informal care and/or formal home care, if specialized care is necessary, by delaying the institutional care. This result also has important policy implication for higher demand for formal home health care in future years than the simple demographic projection of the size of the individuals with dementia. This finding highlights the fact that quality of family relationship is a significant predictor for institutionalization of dementia patients. This also suggests that potential modifiable target for caregiver intervention policies should include improving family functioning or family social support system.

8. Policy Implications

The findings of this study have important policy implications to address the eligibility criteria for improving access to LTC programs for the elderly individuals with dementia in the US. The remarkably strong relationship of the need for supervision with formal home care has implication for the design of formal home care services. It confirms that the eligibility criteria chosen for LTC needs by restricting only with activity of daily living, doesn't capture the unique nature of the functional limitations and LTC needs of people with dementia. This also corroborates with the Panel's recommendation that the LTC needs should be based on measures of impaired functioning that are characteristics of people with dementia.

Secondly, this study finds that caregiver's need characteristics in addition to the needs for the impaired persons significantly influence the amounts of informal and formal home health care and nursing home care. Therefore, to formulate long-term care policy to ensure better health care needs of people with dementia, it is important to consider the negative effects of caregiving burden, especially in the allocation of in-home services. Any intervention policy targeted towards reducing caregivers' stress and burden would be helpful in future years to motivate families to provide informal care to the individuals with dementia. It has already been raised significant concerns and challenges among policy makers of how to provide better and efficient health care supports to people with dementia and this will impose huge burden on the US health care system in coming years.

Therefore, the negative effect of caregiving on caregivers' physical and mental health is an important policy question of reducing caregiving burden and encouraging families to provide informal care in future years. With the growing demand for informal care in coming years, initiatives such as tax breaks for family caregivers, flexible schedules for working caregivers, employers offered time off could reduce the burden of caregiving by encouraging more families to provide informal care for their family members. Also interventional policies targeting caregiver knowledge about caregiving, the availability of social support, caregivers' feelings of depressions, anxiety, stress and well-being may produce significant improvement in caregiver burden and motivation for providing care.

9. Conclusions

This study explores *predisposing*, *enabling* and *need* characteristics that determine jointly the level of informal support and the use of formal health care services of people with dementia or cognitive impairments. It also focuses on the characteristics of the family caregiver as well as the impaired person to understand the set of factors that influence the use of both informal and formal health care supports. Moreover, caregiver's motivation to provide care is an important predictive factor of both informal care and the use of formal health care services.

The analysis shows that the amount of informal care received increases with the need for supervision to protect the consequences of impaired functioning at a much greater rate then does formal care under the same circumstances. This suggests that with an increase in care needs, family and friends step in to provide the bulk of care.

The above findings regarding informal care also highlight the equity choices of who should receive public long-term benefits. In other words, the valuation of informal care implicitly or explicitly affects the choice of eligibility criteria and benefit levels of long term care programs. The family members providing informal care incurs substantial financial burden i.e. long-term cost. Caregivers face uncompensated cost of providing informal care to an individual with dementia for long time. Most of the dementia caregivers are women and therefore, women bear a disproportionate share of uncompensated cost of providing informal care.

Future research can be extended by incorporating uncertainty into informal-formal care decisions as it will allow to acknowledge the dynamic nature of caregiving and to examine the relationship between informal care and formal health care services over time. To incorporate the time effect on the formal and informal care decision, one needs to introduce uncertainty into the optimal decision problem. For example after providing informal care for some time, an informal caregiver might value formal care more than informal care, one therefore needs to introduce real life restrictions into the decision between informal-formal cares. Another possible extension could be to examine the dynamic nature of the predictive factors on the levels of informal and formal care services that certainly provides more insight on forecasting future health care needs of people with dementia in the US.

Appendix.

Table 1. Variables and descriptive of the sample (n=273)

Name	Description	Mean	SD
Caregivers' characteristics			
Age	years	61.32	13.79
Marital status	1, if married	0.70	0.45
Gender	1, if female	0.74	0.44
Education	1, if high school graduate or above	0.82	0.38
Race	1, if White	0.70	0.46
Self-reported health	1, if excellent/very good/ good	0.73	0.45
Stress	1, if feel more stressful	0.68	0.46
Social interaction	1, if spend less time with other family members	0.46	0.49
Income	income >0	10,008	19,299
Work schedule	1, if changes work schedule	0.41	0.49
Informal care	log (# of hours provided last month)	4.10	2.04
Relationship	1, if spouse	0.72	0.85
Living status	1, if living in same household with the patient	0.50	0.50
Leisure time	1, if reduce leisure time activity	0.52	0.50
Physical activity	1, if reduced	0.57	0.49
Feel good	1, if providing care feel good	0.87	0.333
Patient well-being	care prevents patient from getting worse	0.58	0.49
Paid work	1, if working for pay	0.41	0.50
work per week	# of hours per week	13.87	20.46
Strain with ADL	on scale (0-2, 0; no strain, 2; lot of strain)	1.09	1.17
Strain with IADL	same as ADL strain	0.71	0.73
Perceived health	1, if change	0.63	0.48
Patient Characteristics			
Age	years	85	6.75
Gender	1, if female	0.63	0.48
Marital status	1, if married	0.69	0.46
Education	1, if high school or above	0.17	0.37
Race	1, if white	0.74	0.43
Hispanic	1, if not Hispanic	0.91	0.28
Self-reported	1, if excellent/very good/		

health	good	0.44	0.49
ADL[9]	# of ADL limitations	3.5	12.4
IADL[10]	# of IADL limitations	4.2	14.2
<u>Insurance</u>			
Medicare	1, if has Medicare	0.96	0.19
Medicaid	1, if has Medicaid	0.25	0.43
Long-term insurance	1, if has long-term insurance	0.05	0.23
<u>Heath Care utilizations</u>			
Hospital stays	log of # of hospital stays past year	0.86	1.15
Nursing home stays	log of # of nursing home stays past year	1.47	2.30
Home health care	# of help	1.34	1.46
Paid care	1, if paid home heath care has arranged	0.464	0.499

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[9] Activity of Daily Livings: six categories were considered: problems with bathing, eating, dressing, toileting, getting out of bed, getting across the room.

[10] Instrumental Activity of Daily livings: problems with preparing meals, grocery/shopping, making telephone calls, taking medications and managing money.

Table2. Predictive factors of Informal care and the use Formal health care services**.**

		Formal care services		
Variables	Informal care	Home health	Nursing home	Hospital
<u>Patient level</u>				
<u>*Predisposing*</u>				
Age	0.002(0.80)	0.032(0.01)***	0.005 (0.73)	0.006(0.71)
Female	0.102(0.70)	-0.053(0.84)	-0.536(0.16)	0.006(0.98)
Married	1.21(0.25)	0.028(0.86)	-0.478(0.15)	-0.222(0.71)
White	0.963(0.16)	0.925(0.02)**	0.412(0.49)	0.387(0.32)
Hispanic	-0.536(0.70)	0.491(0.55)	-1.42(0.21)	-0.001(0.93)
Relation	-0.099(0.80)	-0.404(0.09)*	0.441(0.21)	-0.139(0.17)
<u>*Enabling*</u>				
Wealth	0.000(0.99)	0.004(0.18)	0.012 (0.02)**	0.000(0.78)
Living together	1.22(0.00)***	-0.688(0.00)***	-1.99(0.00)***	-0.011(0.95)
Medicaid	0.098(0.61)	0.013(0.85)	0.689 (0.03)**	-0.060(0.77)
Medicare	-0.192(0.79)	0.752(0.08)*	0.474(0.45)	0.495(0.24)
Have child	0.032(0.55)	0.028(0.42)	-0.033 (0.56)	0.019(0.55)
<u>*Need*</u>				
ADL limitation	0.019(0.81)	0.032(0.49)	0.259(0.00)***	0.119(0.01)***
IADL limitation	0.063 (0.55)	0.086 (0.11)	0.016(0.89)	-0.068 (0.18)
Safety	1.81(0.00)***	0.525(0.02)**	0.677(0.05)*	0.061(0.74)
Self-reported health (1: excellent, 5: poor)	0.558 (0.10)*	-0.552 (0.00)***	-0.759 (0.01)***	-0.134(0.49)
Chronic conditions	0.035(0.75)	0.013(0.81)	-0.218(0.02)**	0.074(0.23)
Incontinence	0.520(0.10)*	0.349(0.06)*	0.235(0.40)	-0.297(0.10)*
<u>Health behavior</u>				
Smoking	-0.089(0.77)	-0.049(0.78)	0.199(0.39)	0.411(0.02)**
Drink alcohol	0.234 (0.84)	0.524(0.47)	0.221(0.84)	0.037 (0.90)
<u>Caregiver level</u>				
<u>*Predisposing*</u>				
Age	0.012(0.36)	0.001(0.83)	0.204(0.06)**	0.010(0.15)
Female	0.156(0.67)	-0.410(0.06)**	-0.260(0.42)	-0.258(0.22)
Married	-0.098(0.77)	-0.067(0.73)	-0.026(0.90)	-0.058(0.76)
White	-1.19(0.05)**	-0.539(0.13)	0.240(0.65)	-0.290(0.41)
Hispanic	0.705(0.58)	0.025(0.78)	1.35(0.22)	-0.005(0.99)
<u>*Enabling*</u>				
Education	-0.183(0.58)	0.204(0.25)	0.255(0.38)	-0.139(0.46)
Income	0.166(0.64)	0.0290.89)	0.236(0.44)	0.094(0.62)
<u>*Need*</u>				
Activity restrictions	0.210(0.14)	0.072(0.36)	0.096(0.41)	0.052(0.49)
Perceived health	-0.62(0.06)*	-0.086(0.66)	0.479(0.10)*	0.230(0.23)
Physical stress	1.32(0.00)***	0.405(0.02)**	-0.355(0.23)	0.401(0.47)
Emotional stress	0.496(0.16)	0.531(0.00)***	-0.284(0.35)	0.017(0.92)
<u>Motivation</u>				
Feel good	0.651(0.16)	0.386(0.13)	-0.174(0.65)	-0.503(0.05)**

a. p-values are in the parenthesis, b.* Significant at 10% level, ** significant at 5% level, *** significant at 1% level.

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