

Altruism and Informal Care for Dementia

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Abstract

Informal care is an important source of care for persons with dementia. The primary objective of this study is to explore the factors that affect the choice to provide informal care and test if altruistic attitudes change the mix of formal and informal care given to patients with dementia. Using the Aging Demographic and Memory Study dataset, we analyze how patient and caregiver characteristics affect the use of informal and formal healthcare services by dementia patients, focusing on the role of altruism. Assuming that the total care provided is an unobserved mix of informal and formal care, we use a latent class model to test if direct altruism increases the probability that informal care is included in the care plan. Greater patient need, as measured by limitations in the number of activities of daily living, and having three or more comorbid conditions decreased the probability of having only informal care, while needing supervision increased the probability of having only informal care. The direct altruism has a positive and significant marginal effect on increasing the probability of providing only informal care and decreasing the probability of being in the mix category of informal and formal category. Our model suggests that altruism in the form of caregivers' pleasure from providing care increases the amount of informal care used. Although not socially inefficient, it does raise the cost of care as part of the cost is "spent" on caregiver's pleasure. We find empirical evidence in support of this theoretical implication.

Keywords: Informal care, dementia, altruism, long-term care

1. Introduction

Dementia, the deterioration of cognitive ability that impairs independent functioning, affects 5% to 10% of Americans aged 65 or above (Langa et al. 2004). Much of the care that dementia patients need is provided outside the formal health care system. Formal home and institutional health care services provide only about 25% of the care for individuals with Alzheimer's disease; nonprofessional family and friends provide the rest (Schubert et al. 2008; Zhu et al. 2008). In 2009, 11 million unpaid caregivers provided 12.9 billion hours of informal care to individuals with AD and other types of dementias (Alzheimer's Association. 2010). In this paper, we explore the factors that affect the choice to provide informal care and test if altruistic attitudes change the mix of formal and informal care given to patients with dementia. Using the Aging, Demographics, and Memory Study (ADAMS) dataset, we organize our analysis around the Anderson Behavioral Model of Health Care (Anderson and Aday 1978) which identifies *predisposing* demographic and social factors that affect a person's inclination to use services, *enabling* factors that facilitate or inhibit the access to health care services and *need* factors which are defined by the severity of the illness.

Most of the caregiving literature on long-term care decisions for elderly persons finds that patient needs are the main predictors of the demand for care (Bolin et al. 2008; Bosang 2009; Charles and Sevak 2005; Armingon et al. 2005; Van Houtven and Norton 2004; Lo Sasso and Johnson 2002). This perspective ignores that altruistic values on the part of caregivers (Grant and Nolan 1993; Shultz and Martire 2004) may elicit more informal care than would be given in its absence. In this paper we explore how altruism plays a role in how much formal and informal care a dementia patient receives.

The remainder of this paper is organized as follows. The next section presents our conceptual framework that explains the caregiving problem from the perspective of the caregiver. Section 3 provides a description of the ADAMS data and the variables used in the empirical model. The empirical model and other econometric issues are discussed in section 4. Section 5 has the empirical results, and section 6 suggests policy implications and concludes the paper.

2. Conceptual Framework

We assume a surrogate decision maker (Black et al. 2009) chooses the care plan for each patient with cognitive impairment.ⁱ The decision maker chooses her own consumption and the patient's care plan, and is also the provider of any informal care. We allow altruism in two potential forms; first that the caregiver's utility is greater if the patient achieves a higher health status, which we term indirect altruism (Becker 1993), and second that the caregiver derives direct satisfaction from providing care (Grant & Nolen 1993, Zhu, Moore & Clipp, 2003), which we term direct altruism. Hence the caregiver chooses the amount of the informal care, t_c , leisure, t_l , and the amount of formal care, F , to maximize her own utility,

$$U = U^c(C, t_l, h^p(t_c, F, x) | z) + \gamma * t_c \quad (1)$$

where C is the caregiver's own consumption, with a positive marginal utility, t_l is the time the caregiver spends in leisure, $h^p(t_c, F, x)$ is the patient's health state which depends on the amount of formal care, F , and informal care, t_c provided, x is a vector indicating the patient's innate health status (for example, fragility that does not depend on the amount of care received) and other characteristics and z are the caregiver characteristics. The patient's health production function is strictly concave where the marginal products of health with respect to formal care and informal care are positive ($h_{FF}^p < 0, h_{tc}^p < 0$), and health increases at a decreasing rate as formal care and informal care are increased ($h_{FF}^p < 0, h_{tc}^p < 0$), and there is smooth substitution between formal and informal care. If there is indirect altruism, $\partial U^c / \partial h^p > 0$. The utility function $U^c(\mathcal{G})$ is an increasing a strictly quasi-concave function and well-behaved locally to ensure an interior optimum. Direct altruism is captured by the additive term $\gamma * t_c$ in the utility function (Fevang E et al. 2008). If γ is positive, then the caregiver gets direct utility from giving care. If γ is zero, then the caregiver gets no direct utility from providing care although indirect altruism can be a possibility.ⁱⁱ

Labor income, earned at rate of w per unit of time spent in labor (t_{ls}), and nonlabor income (family wealth) (y_0) are spent on formal care (F) and consumption (the *numeraire* good) giving a monetary budget constraint of:

$$C + p_f F = w t_{ls} + y_0 \quad (2)$$

Total time (T) is restricted as:

$$T = t_l + t_{ls} + t_c \quad (3)$$

Combining equations (2) and (3) gives the total income constraint

$$C + p_f F = w(T - t_c - t_l) + y_0 \quad (4)$$

The right hand side of (4) is the caregiver's total income (nonlabor plus labor) and the left hand side is the total expenditure spent on consumption and formal care. Patient characteristics enter into the problem through x in the health status function, while the caregiver's final utility depends on his or her own characteristics.

The Lagrangian function for this problem is

$$L = U^c(C, t_l, h_p(t_c, F | x) | z) + \gamma * t_c + \lambda [p_f F + C + w(t_c + t_l) - wT - y_0] \quad (5)$$

First order conditions are

$$L_{t_c} = \left(\frac{\partial U^c}{\partial h^p} \frac{\partial h^p}{\partial t_c} \right) + \gamma + \lambda w = 0 \quad (6)$$

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

$$L_1 = \frac{\partial U^c}{\partial t_1} + \lambda w = 0 \tag{8}$$

$$L_2 = p_f F + C + w t_c + w t_1 - w T - y_o = 0 \tag{9}$$

Combining (6) and (7) we find

$$\frac{\frac{\partial U^c}{\partial h^p} \frac{\partial h^p}{\partial t_c} + \gamma}{w} = \frac{\frac{\partial U^c}{\partial h^p} \frac{\partial h^p}{\partial F}}{p_f} \tag{10}$$

Equation (10) indicates that the optimal choice of t_c and F requires that the marginal utility per additional dollar spent for informal care (in terms of the opportunity cost of foregone wages) must equal the marginal utility per additional dollar spent on formal care. The marginal utility of informal care consists of two parts – the direct utility increment of γ and the indirect utility increment from improved patient health. Notice that if $\gamma = 0$ (10) becomes

$$\frac{\frac{\partial U^c}{\partial h^p} \frac{\partial h^p}{\partial t_c}}{w} = \frac{\frac{\partial U^c}{\partial h^p} \frac{\partial h^p}{\partial F}}{p_f} \Rightarrow \frac{\frac{\partial h^p}{\partial t_c}}{w} = \frac{\frac{\partial h^p}{\partial F}}{p_f} \tag{11}$$

Equation (11) has an interesting interpretation; in the absence of direct altruism, utility maximizing behavior on the part of caregivers results in a mix of formal and informal care that is congruent with what is normally construed as an efficient input mix. Moreover, if $\gamma > 0$ we see that

$$\left(\frac{\partial h^p}{\partial t_c}\right) / w < \left(\frac{\partial h^p}{\partial F}\right) / p_f.$$

Implied from this relationship is that *for the same cost* more health is achieved by patients with caregivers who do not get direct pleasure from providing care than by patients with caregivers who do get direct pleasure from providing care. This is shown in Figure 1. Caregivers with positive γ “spend” part of the opportunity cost of foregone wages on their own direct pleasure instead of indirectly on the utility received from improved patient health.ⁱⁱⁱ If there is only indirect altruism, this is not the case.

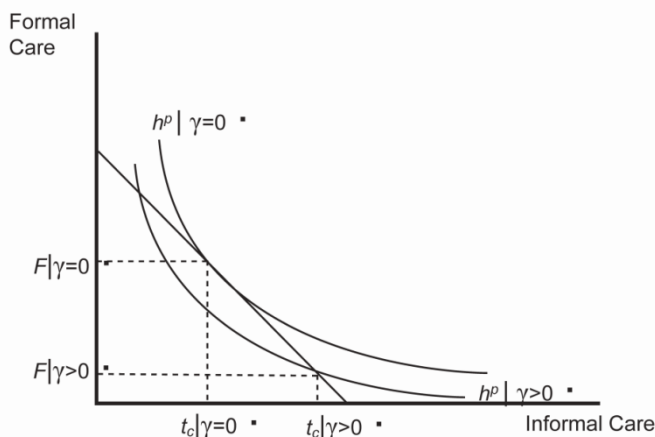


Figure 1. Influence of γ on optimal health production

Of course when $\gamma > 0$, it is likely, that a greater share of total available resources is devoted to patient care imposing a less than proportionate decrement in formal care – the greater share of resources comes, at least in part, from decreased caregiver consumption. Moreover, indirect altruism, which is reasonably correlated with direct altruism, would also lead to a larger share of available resources devoted to patient care, hence, the net effect of a positive γ on patient health is an empirical issue that depends on the elasticity of substitution between formal and informal care in the health production function and the elasticity of substitution between consumption and leisure and patient health in the caregiver’s utility function. It also explains why some studies

have found formal and informal care to be substitutes (Bolin et al. 2008; Bonsang 2009; Charles and Sevek 2005; Armington et al. 2005; Van Houtven and Norton 2004) while others found them to be complements (Bolin et al. 2008; Langa et al. 2001b). Our question of interest has to do with *direct* altruism and how it affects the mix of formal and informal care. We take two approaches to this problem. First, we assume that the total amount of care provided is a latent variable, y_i^* which is an unobserved mix of formal and informal care chosen to maximize (1). We then construct a variable on the amount of informal care a patient receives; whether the care plan is only informal care, a mix of formal and informal care, or only formal care and consider this an ordering of the strength of informal care as a part of the total care plan. We use an ordered probit analysis to test if direct altruism increases the probability that informal care is included in the care plan.

Two different probit models were estimated. The first was a three-category model of “only”, “some” or “no” informal care, including those who use institutional care. Because patients requiring institutional care may be qualitatively different from those requiring only out-patient care, we performed a second analysis limiting our data only to the population that used no institutional care, and thus tested whether direct altruism increases the probability that only informal services are used.^{iv}

3. Methods

3.1 Sample

The Aging Demographics and Memory Study (ADAMS) is a cross-section sample of 1,770 individuals of age 70 or older, selected from the Health and Retirement Survey, (HRS- 2000 or 2002 waves depending on the timing on recruitment into ADAMS) based on the self-or-proxy reported cognition score. The sample is stratified to ensure a sufficient number of respondents across the full range of five cognitive levels ranging from “low functioning” to “high normal”.^v The ADAMS wave -A assessment occurred between July 2001 and December 2003 and clinical assessments tests were performed on 856 respondents. Full details of the ADAMS sample design and selection methods are described in other studies (Langa et al. 2005; Plassman 2007). Figure 2 describes the ADAMS sample in our study.

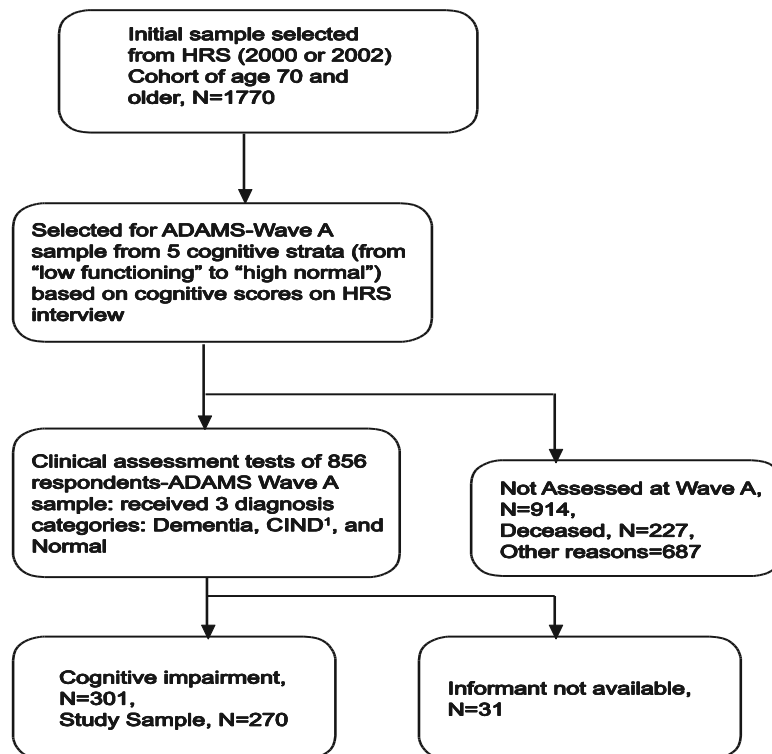


Figure 2. ADAMS sample used in this study

Description of ADAMS Data:

ADAMS provides in-depth information on patients' limitations of independent functions of daily living,^{vi} utilization of formal health care services, including nursing home stays, inpatient hospital stays, home health care services and physician visits, informal caregiving, patient's demographic and socioeconomic characteristics.

For caregivers, ADAMS includes information on demographics, positive attitudes about informal caregiving, and caregiving time that gives a comprehensive picture of a family's provision of informal care associated with cognitive impairment and dementia.^{vii} We restrict our study sample to respondents diagnosed as cognitively impaired or demented at the end of ADAMS Wave A (N=301) assessment. The sample was further shortened (N=270) due to either the nonavailability of appropriate informants or patients' health problems that prevent informants to participate in the study. Linking the ADAMS to the expansive HRS data on health, health care utilization, informal care, economic resources and behavior provides a unique opportunity to study factors influencing the demand for informal care and various types of formal care services. Descriptive statistics for the variables used in our model are provided in Table 1.

Table 1. Variables and Descriptive of Study Sample (N=270)

Variables	Description	Mean (SD)
<u>Predisposing Caregiver</u>		
Age (21-93)	Years	61 (13.79)
Gender	Female	0.73 (0.44)
Race	White	0.65(0.47)
	African-American	0.23(0.43)
	Other	0.12(0.31)
Ethnicity	Hispanic	0.12(0.31)
<u>Patients</u>		
Age (70-110)	years	85 (6.75)
Gender	Female	0.63(0.48)
Marital Status	Married	0.28(0.44)
Race	White	0.69(0.46)
Ethnicity	Hispanic	0.11(0.31)
<u>Enabling Caregiver</u>		
Spouse	if spouse	0.22(0.41)
Child	if child	0.51(0.50)
Other	Family/Friends	0.27(0.44)
Education	some college	0.56(0.50)
Feel good	feel good	0.87(0.34)
	by providing care	
Wealth (-700-2160404)	Dollars	1500 872 (276 704)
Work for Pay		0.41(0.49)
Earnings (97-100000)	those worked	24 452 (22 518)
<u>Patient</u>		
Marital status	if married	0.70(0.45)
Medicare		0.95(0.19)
Medicaid		0.25(0.44)
Long-term insurance		0.05(0.23)
<u>Need</u>		
<u>Patient</u>		
ADL ¹ (0-6)	number of limitations	2.8 (2.3)
IADL ² (0-5)	number of limitations	3.36 (1.8)
Supervision	if need help	0.69(0.46)
Comorbidity	if >3 conditions	0.35(0.48)
CDR ³ (0-3)	dementia severity	1.5 (1.2)
<u>Outcome Variables</u>		
Informal care ⁴ (0-646)	hours/month	195
Formal home care ⁵ (0-6)	number of areas	1.35 (1.46)
Institutional care ⁶ (0-365)	number of nights	72 (130)

Notes: Ranges for continuous variables are shown in the parentheses. For consistency, both the mean and standard deviation for binary variables are reported, even though they carry similar information. ADL includes

functional limitations in activities in daily livings in 6 areas such as bathing, eating, dressing, toileting, getting across the room, and getting out of bed. 2. Instrumental Activity of Daily livings: problems with preparing meals, grocery/shopping, making telephone calls, taking medications and managing money; 3. Dementia rating scale (0-3); 4. Total hours spent in active caregiving, supervision, and transportation per month; 5. Formal care help needed in different areas of IADLs, and skilled nursing care; 6. Total number of nights spent in hospital and nursing home in the year before the survey.

3.2 Measures

It is useful at this point to further clarify the *predisposing*, *enabling*, and *need* factors of both patients and caregivers in the context of our empirical specification. The use of health care services is partially dependent on the predisposition of the individual towards health services as suggested by demographic, social and attitudinal characteristics.^{viii} These factors are known as *predisposing* variables. *Enabling* factors measure how easy it is for individuals to access health services. The patient's state of illness (both self-perceived and evaluated) determines the *need* variables.

Predisposing variables in our data include patient and caregiver socio-demographic characteristics (age, gender) and social structures (education, race/ ethnicity) (Anderson and Aday 1978; Anderson 1995; Bass and Noelker 1987) and if the caregiver is the patient's child. *Enabling* factors include family wealth and the availability of insurance (Medicare, Medicaid and Long-term care) which increase access to formal care services, and if the patient is married, could increase the number of potential caregivers. We also include the caregiver's education level as an *enabling* factor as a measure of the ability to perform care, and knowledge about alternatives and the caregiver's implicit wage (income earned per week divided by hours not spent in informal care) as a measure of his or her opportunity cost.

Need factors include the patient's severity of cognitive impairment as measured by severity of cognitive impairment, the number of limitations noted in activities of daily living (ADL), instrumental activities of daily living (IADL) and the need for regular supervision in one or more of the ADL or IADL. The patient's severity of cognitive impairment was measured by the clinical dementia rating scale (CDR). The CDR reflects an indirect evaluation of cognition and functional performance based on information obtained from both the informant and subject during the course of the evaluation. The CDR rating was assigned for all subjects, regardless of dementia status. Supervision needs measure whether the degree of cognitive impairment interferes with a person's judgments in decision making capacity, impulsive behavior, and ability to complete daily activities without substantial supervision. Finally, because multiple chronic conditions may require more intensive caregiving for dementia patients, we include a binary variable indicating whether the patient has 3 or more comorbid chronic conditions.^{ix}

3.3 Summary Statistics

The typical patient was 85-year-old who had less than a high school education. Twenty-eight percent of the patients were married and 63 percent were female, 69 percent were White non-Hispanic, 20 percent were African American non-Hispanic, and 11 percent of study members were Hispanic.

About 75 percent of the patients in the sample needed assistance with ADL and 90 percent needed help with IADL.^x Seventy-one percent needed both type of help, and 69 percent needed assistance with supervision. Health insurance coverage reflects the advanced age of most dementia patients, with 96 percent of patients being covered Medicare and about 27 percent also having Medicaid – about 25 percent were covered by both Medicare and Medicaid. Only 5 percent of the patients had private long-term care insurance. The average CDR score is 1.5 which indicates the moderate level of dementia.

Caregivers averaged 61 years of age and had more than a high school education. Almost three-fourths of the caregivers (73 percent) were female. Over half (51 percent) of caregivers were adult children, 22 percent were spouses and 27 percent were friends and other family members. Forty percent of the caregivers worked for pay with average earning per year of \$10,008.^{xi} Ethno-racial composition includes 70 percent Caucasians, 30 percent African American or others and 12 percent Hispanic. A total of 50 percent of caregivers lived with patients in same households. We capture altruism by the variable "feel good" (a binary variable) based on the survey question, "Has providing care made you feel good about yourself?" Approximately 87 percent of caregivers responded that providing care made them feel good.

We consider informal care as the total time spent on active care, supervision and transportation per month.^{xii} On an average, 195 hours of informal care was provided per month. Because some caregivers gave incomplete answers, a bracketed variable was created for those 10 based on assumptions about the intensity of care-giving

per day for dementia and impaired persons (VanHoutven and Norton 2004). Using 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. 2001a). The analysis was also run without those 10 cases and no significant change was found.^{xiii} Two types of formal care utilization were considered: formal home health care, which is primarily based on eligibility criteria; and institutional care, which depends on financial resources (personal/family wealth, caregivers' wages). The utilization levels are measured by two separate variables: (1) the natural log of nights in a nursing home or hospital^{xiv}, and (2) the number of formal home health care services used. On an average, respondents spent 72 nights in a nursing home or hospital and used 1.35 specific formal home health care services.

Table 2 shows the correlation between the types of care used. There is a strong positive relationship between formal home care services and institutional care, which probably indicates both types of formal care are driven by need, and patients progressively move from lower need (formal home care) to higher need (institutional care). Surprisingly, there seems to be little relationship between the amount of informal care provided and the number of formal home care services used, indicating that informal and formal home care neither substitute nor complement each other. However, there is a significant negative relationship (as indicated by the -0.17 value of the correlation coefficient) between the amount of informal care provided and institutional care, indicating that when patients are institutionalized, the amount of informal care falls. If the negative correlation is because informal care and institutional care are substitutes, there is a potential that informal care delays institutionalization. However, it may be simply that there is less opportunity for informal care if a patient is institutionalized.

Table 2. Correlations between informal and formal care

Variables	Informal care	Formal home care	Institutional care
Informal	1	0.05	-0.17***
Formal home care	0.05	1	0.33***
Institutional care	-0.17***	0.33***	1

*** $p < 0.001$

4. Results and Discussion

4.1 Probit Analyses

Table 3 reports the results when we used the entire sample for an ordered probit estimated with *Stata 11* (STATA Corporation, College Station, TX) on an ordering on the share of formal care a patient received. Hence, we use three categories that reflect a decrease in the share of care a patient receives; only informal care, a mix of informal and formal care, and no informal care. For ease of interpretation, the probit estimates were translated

into marginal effects with respect to independent covariates and we report the Wald statistic = $\left(\frac{\hat{b}_j}{SE(\hat{b}_j)} \right)^2$

for each estimate. Our probit results show the average of absolute increase/decrease in the probability of being in a particular care plan category with respect to a unit change in each independent variable across all sample members. Six variables had statistically significant (at conventional levels of significance) marginal effects on the extreme values (only informal care and no informal care). We discuss only the effects on "only informal care" as the impact on "no informal care" is of the opposite sign. As expected, married patients are more likely to receive only informal care. Consistent with other studies (Toseland et al. 2002; Wimo et al., Bass et al. 1992; Gill et al. 1998), greater patient need, as measured by limitations in the number of ADL, and having 3 or more comorbid conditions decreased the probability of having only informal care, while needing supervision increased the probability of having only informal care. Wealthier patients and patients with Medicaid insurance are less likely to use only informal care in the total care plan.

Table 3. Predicted Probabilities and Marginal Effects from the Ordered Probit Model[§]
 [Dependent variable: Care mix (3 ordered categories; Only IC, mix of IC and FC, No IC)]

Variables	Only IC	Mix of IC & FC	No IC
Predicted Probability	0.23	0.65	0.11
95% CI	[0.18, 0.27]	[0.59, 0.71]	[0.07, 0.16]
Patient's characteristics			
<u>Predisposing</u>			
Age	-0.00 (1.63)	0.00 (1.44)	0.00 (1.61)
Female	0.05 (1.58)	-0.02 (1.34)	0.04 (1.58)
White	0.09 (2.60)	-0.03 (2.56)	-0.05 (2.28)
Hispanic	-0.07 (0.74)	0.02 (0.65)	0.04 (0.75)
<u>Enabling</u>			
Wealth	-0.16 (5.76)**	0.06(3.89)**	0.10(5.47)**
Medicare	0.03 (0.12)	-0.01 (0.12)	-0.02 (0.11)
Medicaid	-0.10 (3.57)*	0.03 (2.56)	0.06 (3.57)*
Long-term insurance	0.12 (1.46)	-0.04 (1.27)	-0.07 (1.27)
Married	0.20 (7.02)***	-0.07 (4.79)**	-0.13 (6.65)***
<u>Need</u>			
ADL	-0.03 (8.01)***	0.01 (5.33)**	0.02 (3.24)*
IADL	-0.01 (0.62)	0.005 (0.56)	0.01 (0.75)
Supervision	0.10 (1.64)	-0.02 (1.63)	-0.05 (2.01)
Comorbidity ^a	-0.13 (8.29)***	0.05 (5.06)**	0.08 (10.24)***
CDR ^b	0.08(16.0)***	0.03(9.0)***	0.05(8.94)***
Caregiver's characteristics			
<u>Predisposing</u>			
Age	-0.00 (0.47)	0.00(0.46)	0.00(0.07)
Female	0.05 (0.98)	-0.02 (0.86)	-0.03 (0.79)
Married	0.01 (0.09)	-0.00 (0.09)	-0.01 (0.13)
Child Caregiver	0.06 (1.44)	-0.02 (1.27)	-0.04 (1.27)
<u>Enabling</u>			
Education	-0.01 (0.13)	0.01 (0.13)	0.01 (0.07)
Opportunity cost	-0.00 (0.84)	0.00 (0.79)	0.00 (0.77)
Spouse	-0.08 (0.62)	0.03 (0.64)	0.05 (0.47)
<u>Altruism</u>			
Feel good	0.14 (5.24)**	-0.05 (3.98)**	-0.09 (5.06)**

Note: § Wald statistics are shown in the parentheses. Any possibility of heteroskedascity was taken into account by calculating the White heteroskedascity-consistent robust standard error in the estimation. *** $p \leq 0.01$, ** $p \leq 0.05$, * $p \leq 0.10$. ^a having 3 or more chronic conditions; ^b dementia rating scale. Categories of dependent variable: 1=only informal care; 2= mix of informal and formal care; and 3= no informal care.

What is more interesting is the marginal effects on the mix of formal and informal care. The positive marginal effects, at conventional significance levels, for ADL, dementia severity and comorbidity indicate that the shift is away from informal care towards formal care as these increase, while the negative coefficient on supervision coupled with its impact on only formal care and only informal care suggests that, holding all else constant, if this is the stimulant for care, it is more likely given informally.

For the most part these results are mirrored for the subpopulation who used no institutional care when estimates are evaluated at conventional significance levels,^{xv} and strengthen the interpretation of the three category results. This estimation has a Chi-square of 53.39 and a pseudo R-square of 0.41. Being Hispanic or White decreased the probability of using only informal care, and both measures of need, ADL and IADL also decreased the probability of having only informal care. For this subsample, family wealth did not decrease the probability of having only informal care. Although this may be surprising given what was found for the full sample, we interpret this result as indicating that if caregiver has greater family wealth, patients are more likely to be

institutionalized. Being on Medicare increased the probability of using only informal care, while patients with Medicaid decreased that probability. Finally, patients with long-term care insurance are more likely to use informal care. This result is quite surprising given the fact that individuals purchase long-term care insurance in order to financially support the use of formal care services when the need is realized. However, complexities in navigating the current long-term care system may result the underutilization of needed services.

Once again, our primary interest is in the altruism variable, as measured by the feel good variable. When using all three categories "feel good" has a positive marginal effect with a *p-value* of 0.05, increasing the probability of being in the 'only informal care' category (and, consequently, decreasing the probability of being in the 'no informal care' category), and decreasing the probability of being the mix category with a similar *p-value* of 0.05. There was no marginal effect of being in the mix of care category, nor did we find a statistically significant result with a *p-value* of 0.10 or smaller for the subsample of patients who used no institutional care. Together the two probit analyses indicate that patients are kept out of institutional care when the caregiver has direct altruism, but there is no strong impact of altruism on the mix of formal and informal home care services.

Table 4 shows predicted probabilities for when "feel good"=1 and when "feel good"=0, holding all continuous variables at their mean values and other dummy variables at 0. The probability of receiving 'only informal care' increased by about 17 percentage points (with most of this increase coming from those using a mix of services) and the marginal effect is statistically significant at a *p-value* of 0.02. We interpret this to mean that direct altruism reduces the probability that a caregiver will use formal care as a respite for themselves.

Table 4. Predicted probabilities and marginal effects for "Feel Good"

	Only IC ^a	Mix of IC and FC ^b	No IC
Predicted Probability (Case 1)	0.59 [0.21, 0.97]	0.40 [0.39, 0.41]	0.009 [-0.01, 0.03]
Predicted Probability (Case 2)	0.42 [0.03, 0.82]	0.54 [0.52, 0.56]	0.02 [-0.03, 0.09]
Difference	-0.17 [-0.18, 0.09]	0.15 [0.09, 0.17]	0.01 [0.008, 0.011]
Marginal Effect ^c (Feel good)	0.12 [-0.01, 0.23]	-0.03 [-0.08, 0.01]	-0.08 [-0.16, 0.01]

^a IC stands for Informal care; ^b stands for formal care, both formal home health care and institutional care.

Case 1: Feel good=1 (Specifications for dummy independent covariates: a male, married, White, non-Hispanic patient needing help with supervision, incontinence, had a female adult child caregiver, married, at least high school education, all other continuous variables were fixed at their mean values).

Case 2: Feel good=0 (same specifications as above)

^c This is an average marginal effect rather marginal effect at mean. This means that discrete change in feel good from 0 to 1 was calculated for all sample members then calculated the average of all individual marginal effects in order to get the overall effect. This method was used as the current practice favors averaging individual marginal effects when it is possible to do so (Greene 2000).

5. Summary, Limitations, and Conclusions

We explored what patient and caregiver factors influence the type of care given to patients with dementia, using an ordered probit analysis supplemented with a reduced form analysis. Our findings suggest that the primary determinants of the level and types of care given depend on 'patient need', but that altruism can, on the margin, change the mix of care provided. Our primary question focused on the role of "direct" altruism, in the form of a caregiver deriving pleasure from providing informal care, in the mix of informal and formal care services as a part of the total care plan for patients with dementia. Our main interest was to test whether "direct" altruism increases the probability of receiving informal care in the total care plan. We find strong support for a conjecture that "direct" altruism increases the role of informal care in the total care plan, mostly instead of using institutional care. This is consistent with our theory which predicts direct altruism might decrease the overall quantity of care given when faced with a limited budget for providing care.

Although our results in general supports the health service utilization literature that points to the importance of need variables in predicting health services use (including studies focused on dementia patients), we discuss our results in comparison with two most recent studies (Bolin et al 2008; Bosang 2009) that examined the

relationship between informal and formal care use among older adults. Both studies ignored the role of altruism in the optimal mix of informal and formal care use in the total care plan and hence relationships between two types of care. We show that direct altruism is likely to increase the use of informal care instead of using formal home care and institutional care. This observation may have some important implications for rebalancing long-term care policies.

We note several limitations to this study. First, due to lack of appropriate data, we could not examine the elasticity of substitution between informal and formal care in the health production function. This information would have enabled us to explain the net impact of altruism on overall level of care provided. Second, the cross-sectional data used in this study preclude direct examination of the dynamics of need problems in health services utilization. Since functional abilities predictably decline over the course of the disease, longitudinal data would allow us to see how altruism affects the mix of care as the disease progresses. Third, the measure of direct altruism by the “feel good” variable provides only a gross measure of caregivers’ perceived subjective gain and rewards from giving care, although similar measures have been used elsewhere (Miller 1989). A more comprehensive instrument that measures the intensity of caregiving satisfaction scale (Lawton et al. 1989) could give more insightful inferences.

Our results have some important implications for policy makers who address the long-term care needs for persons with dementia. The strong relationship between needed supervision and the amounts of both types of home health care, and the apparent lack of relationship between needed supervision and institutional care suggests that the present eligibility criteria^{xvi} for ‘long-term care needs’ does not capture the unique nature of the care needs for people with dementia. Because we find support for the idea that direct altruism moves people from institutional care to informal care, it may be that some people in institutional arrangements need not be there; perhaps they are in institutions because no one “cares enough” to provide for them outside of the formal care system, and the formal home care system is not available to them because of strict eligibility requirements for formal home health care services.

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Research Integrity

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References

- Alzheimer’s Association. (2010). *Alzheimer’s disease facts and figures Alzheimer’s & Dementia*, 6(2), 158-194.
- Anderson, R., & Aday, L. A. (1978). Access to medical care in the U.S.: realized and potential. *Medical Care*, 16(7), 533-546. <http://dx.doi.org/10.1097/00005650-197807000-00001>
- Anderson, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behaviors*, 36(1), 1-10. <http://dx.doi.org/10.2307/2137284>
- Argimon, J., Limon, E., Vila, J., & Cabezas, C. (2005). Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. *Alzheimer Disease and Associated Disorders*, 19(1), 41-44. <http://dx.doi.org/10.1097/01.wad.0000160343.96562.8e>
- Bass, D. M., & Noerker, L. S. (1987). The influence of family caregivers on elder’s use of in-home services; an expanded conceptual framework. *Journal of Health and Social Behavior*, 28(2), 184-196. <http://dx.doi.org/10.2307/2137131>
- Bass, D. M., Looman, W. J., & Ehrlich, P. (1992). Predicting the volume of health and social services: integrating cognitive impairment into modified Anderson framework. *Gerontologist*, 32(1), 33-43. <http://dx.doi.org/10.1093/geront/32.1.33>
- Becker, G. S. (1993). Nobel Lecture: The Economic Way of Looking at Behavior. *The Journal of Political Economy*, 101(3), 385-409. <http://dx.doi.org/10.1086/261880>
- Black, B. S., Fogarty, L. A., Phillips, H, Finucane, T., Loreck, D. J., Baker, A., et al. (2009). Surrogate decision maker’s understanding of dementia patients’ prior wishes for end-of-life care. *Journal of Aging and Health*, 21(4), 627-650. <http://dx.doi.org/10.1177/0898264309333316>

- Bolin, K., Lindgren, B., & Lundbrog, P. (2008). Informal and formal care among single-living elderly in Europe. *Health Economics*, 17(3), 393-409. <http://dx.doi.org/10.1002/hec.1275>
- Bonsang, E. (2009). Does informal care from children to their elderly parents substitute for formal care in Europe? *Journal of Health Economics*, 28(1), 143-154. <http://dx.doi.org/10.1016/j.jhealeco.2008.09.002>
- Charles, K. K., & Sevak, P. (2005). Can family caregiving substitute for nursing home care? *Journal of Health Economics*, 24(6), 1174-1190. <http://dx.doi.org/10.1016/j.jhealeco.2005.05.001>
- Diehr, P., Yanez, D., Ash, A., Hornbrook, M., & Lin, D. (1999). Methods for analyzing health care utilization and costs. *Annual Review of Public Health*, 20, 125-144. <http://dx.doi.org/10.1146/annurev.publhealth.20.1.125>
- Fevang, E., Kverndokk, S., & Roed, K. (2008). *A model for supply of informal care to elderly parents*. University of Oslo, Health Economics research Program, Working Paper No.12. Available from URL: http://www.med.uio.no/helsam/forskning/nettverk/hero/publikasjoner/skriftserie/2008/hero_2008_12.html. Accessed March 30, 2012.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinicians. *Journal of Psychiatric Research*, 12(3), 189-198.
- Gill, C., Hinrichsen, G., & DiGiuseppe, R. (1998). Factors associated with formal service use by family members of patients with dementia. *Journal of Applied Gerontology*, 17(1), 38-48. <http://dx.doi.org/10.1177/073346489801700103>
- Grant, G., & Nolan, M. (1993). Informal careers: sources and concomitants of satisfaction. *Health and Social Care in the Community*, 1(3), 147-159.
- Greene, W. H. (2000). *Econometric Analysis*, (International Ed 5th ed). Upper Saddle River (NJ): Prentice Hall.
- Gregory, R., Roked, F., Jones, L., & Patel, A. (2007). Is the degree of cognitive impairment in patients with Alzheimer's disease related to their capacity to appoint an enduring power of attorney? *Age and Ageing*, 36(5), 527-531. <http://dx.doi.org/10.1093/ageing/afm104>
- Health and Retirement Study*. Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant numbers U01AG009740, RC2AG036495, and RC4AG039029), Ann Arbor, MI. <http://hrsonline.isr.umich.edu/>
- Hebert, L. E., Scherr, P. A., Bienies, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer's Disease in the US population: prevalence estimates using the 2000 census. *Archives of Neurology*, 60(8), 1119-1122.
- Heckman J. (1979). Sample selection bias as a specification error. *Econometrica*, 47, 153-161. <http://dx.doi.org/10.2307/1912352>
- Herzog, A. R., & Wallace, R. B. (1997). Measures of cognitive functioning in the AHEAD Study. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 52(Spec No), 37-48. http://dx.doi.org/10.1093/geronb/52B.Special_Issue.37
- Jorm, A. F. (1994). A short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): development and cross-validation. *Psychological Medicine*, 24(1), 145-153. <http://dx.doi.org/10.1017/S003329170002691X>
- Langa, K. M., Chernew, M. E., Kabeto, M. U., Herzog, A. R., Ofstedal, M. B., Willis, R. J., et al. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *The Journal of General Internal Medicine*, 16(11), 770-778. <http://dx.doi.org/10.1111/j.1525-1497.2001.10123.x>
- Lang, K. M., Chernew, M. E., Kabeto, M. U., & Katz, S. J. (2001). The explosion in paid home health care in the 1990s: who received the additional services? *Medical Care*, 39(2), 147-157. <http://dx.doi.org/10.1097/00005650-200102000-00005>
- Langa, K. M., Larson, E. B., Wallace, R. B., Fendrick, A. M., Foster, N. L., Kabeto, M. U., et al. (2004). Out-of-pocket health care expenditures among older Americans with dementia. *Alzheimer Disease and Associated Disorders*, 18(2), 90-98. <http://dx.doi.org/10.1097/01.wad.0000126620.73791.3e>
- Langa, K. M., Plassman, B. L., Wallace, B., Herzog, A., Heeringa, S. G., Ofstedal, M. B., et al. (2005). The aging, demographics, and memory study: study design and methods. *Neuroepidemiology*, 25(4), 181-191. <http://dx.doi.org/10.1159/000087448>

- Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology*, 44(3), P61-71. <http://dx.doi.org/10.1093/geronj/44.3.P61>
- Lo Sasso, A. T., & Johnson, R. W. (2002). Does informal care from adult children reduce nursing home admissions for the elderly? *Inquiry*, 39(3), 279-297. http://dx.doi.org/10.5034/inquiryjrnl_39.3.279
- Miller, B. (1989). Adult children's perceptions of caregiver stress and satisfaction. *Journal of Applied Gerontology*, 8(3), 275-293.
- Ory, M. G., Yee, J. L., Tennsted, S. L., & Shultz, R. (2000). The extent and impact of dementia care: unique challenges experienced by family caregivers. In R. Shultz (Ed.) *Handbook of Dementia Caregiving: Evidenced based Interventions for Family Caregivers*. (pp 1-32). New York, NY: Springer.
- Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., et al. (2007). Prevalence of dementia in the United States: the aging demographic and memory study. *Neuroepidemiology*, 29(1-2), 125-132. <http://dx.doi.org/10.1159/000109998>
- Schubert, C., Boustani, M., Callahan, C. M., Perkins, A. J., Hui, S., & Hendrie, H. C. (2008). Acute care utilization by dementia caregivers within urban primary care practices. *Journal of General Internal Medicine*, 23(11), 1736-1740. <http://dx.doi.org/10.1007/s11606-008-0711-0>
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12(3), 240-248.
- van der Linde, R., Stephen, B. C. M., Matthews, F. E., Brayne, C., & Savva, G. M. (2010). Behavioral and psychological symptoms in the older population with dementia-relationships with socio-demographics, health, and cognition. *BMC Geriatrics*, 10, 87. <http://dx.doi.org/10.1186/1471-2318-10-87>
- Van Houtven, C. H., & Norton, E. C. (2004). Informal care and health care use by older adults. *Journal of Health Economics*, 23(6), 1159-1180. <http://dx.doi.org/10.1016/j.jhealeco.2004.04.008>
- Wimo, A., von Strauss, E., Nordberg, G., Sassi, F., & Johansson, L. (2002). Time spent on informal and formal care giving for persons with dementia in Sweden. *Health Policy*, 61(3), 255-268. [http://dx.doi.org/10.1016/S0168-8510\(02\)00010-6](http://dx.doi.org/10.1016/S0168-8510(02)00010-6)
- Zhu, C., Leibman, C., McLaughlin, T., Scarneas, N., Albert, M., Brandt, J., Blscker, D., et al. (2008). The effects of patient function and dependence on costs of care in Alzheimer's disease. *Journal of American Geriatric Society*, 56(8), 1497-1503. <http://dx.doi.org/10.1111/j.1532-5415.2008.01798.x>
- Zhu, C., Moore, M., & Clipp, E. (2003). Dementia problem behavior and the production of informal caregiving services. *Review of Economics of the Household*, 1, 59-76. <http://dx.doi.org/10.1023/A:1021899414829>

ⁱThe most widely accepted and frequently used measure for cognitive impairment is the Mini-Mental state-Examination score (MMSE). A score of 23 or less indicates cognitive impairment, while a score of 20 or lower indicates moderate to severe level cognitive impairment (Folstein 1975; van der Linde et al. 2010). Care recipients in our study sample average a score of 17 on the MMSE, indicating an inability to understand and retain necessary information long enough to reach a decision (Gregory et al 2007).

ⁱⁱ We assume that caregivers never experience a direct *disutility* (resentment) from providing care. They do, however, suffer an opportunity cost in terms of foregone leisure and consumption if time is devoted to informal care. In our empirical analysis we are able to test for γ directly by the nature of our data which provides information about direct altruism. Unfortunately, we do not have any measures of resentment, hence cannot test for any direct disutility impact.)

ⁱⁱⁱ Because of the value derived from the altruism, this result is not necessarily socially inefficient. It does show, however, that for the production of care for dementia patients, altruism may increase the social cost.

^{iv} We also provide estimates of reduced form equations for each of three types of care (informal care, formal home based care, and institutional care), that include a measure of direct altruism as an explanatory variable. The reduced form estimates do not by themselves give a fully adequate analysis, since they do not control for a standardized level of care implicit in the mix of services used. Measuring this directly would require knowing either the health production function for patient health.

^vThe HRS self-reported cognition score is based on measures of the cognitive function in the Asset and Health Dynamics Among Oldest Old (AHEAD) study. Cognitive score is determined using tests of immediate and delayed free-recall, working memory, knowledge, language, orientation and higher level abstract reasoning based on Wechsler Adult Intelligence Scale-revised (WAIS-R) score (Herzog & Wallace 1997; Jorm 1994).

^{vi}Independent functions of daily living are measured by difficulties with Activity of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL). ADLs are measured in the following areas: problems with bathing, eating, dressing, getting across the room, toileting and getting out of bed. IADLs are measured in 5 categories: problems with preparing meals, grocery shopping, making phone calls, managing money and taking medications. While ADLs are necessary for fundamental functioning (as defined by the above), IADLs are not necessary for fundamental functioning but enable individuals to live independently within a community.

^{vii}ADAMS also provides extensive information about caregivers' stress, depression and other activity restrictions due to the caregiving responsibility. We believe these to be endogenous to decisions about informal care and thus were not included as exogenous factors determining the amounts of formal and informal care used.

^{viii} Health beliefs are attitudes, values; knowledge that individuals have about health and health care services that affect their subsequent perceptions of 'need' and the use of health services (Anderson 1995).

^{ix} The average patient had 3 comorbid chronic conditions

^x A typical patient needing help with ADL needed help with 2.78 specific activities. For IADL this number averaged 3.36 specific activities.

^{xi} This number represents average income of all caregivers including those not working due to caregiving responsibility. Such a low average earning indicates there may be large unmeasured indirect opportunity cost associated with dementia. Caregivers who worked the previous year when not providing informal care had average earnings of \$24,450.

^{xii} The survey questions were phrased as follows: "how many days in the last month did you provide active care, supervision and transportation?" and "days that you provide care, how many hours per day?" To reduce the skewness, we used the log of total informal care hours provided per month. Because some observations had a value of 0 for informal care hours we used log of (1+ informal care hours per month) as the dependent variable (Diehr et al. 1999).

^{xiii} Informal care hours are missing for 5% of the cases. A Heckman (1979) model was used to examine sample selection bias and no evidence of sample selection bias was found due to missing observations of informal care hours.

^{xiv} The use of hospital care and nursing home care is essentially the same for dementia patients except one is for short-term care and the other is for long-term, we combined these two formal care utilization levels by combining the number of nights a patient spent in nursing home or in hospital during the twelve months preceding the survey and labeled it as 'institutional care'. To reduce skewness, we again used log of (1+ number of nights spent in nursing home + number of nights spent in hospital).

^{xv} These results are available upon request.

^{xvi} For both publicly and privately (i.e. third party payer) funded services, eligibility criteria is typically based on functional disability in the specified ADLs (Shultz 2000).



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