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## Three Essays on the Supply of Long-Term Care Services to the Elderly in the U.S.

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## Abstract

Situated in the context of a rapidly aging population, this dissertation examines the implications of supplying long-term care (LTC) services to the elderly in the United States. The first two essays investigate private costs of LTC assistance borne by adult children of elderly parents. In contrast, the third essay focuses on the cost of publicly-provided, formal LTC services.

The first essay analyzes whether adult children devote less time to exercise as time allocation in parental caregiving increases. The empirical model is a system of four correlated equations, where the dependent variables are hours spent caregiving, frequency of moderate and vigorous physical activity, and hours spent in paid work. I use pooled cross-sectional data from the Health and Retirement Study (HRS) for this analysis. Results from joint estimation of the four equations indicate limited evidence of a competition between time spent in caregiving and frequency of physical activity. Parental factors that increase allocation of care time to parents do not comprehensively induce reductions in the frequency of any type of physical activity, nor in hours of work, among either men or women.

The second essay goes beyond time resources and examines whether dementia onset in parents leads to a reduction in adult children's household wealth. Towards this, I construct a longitudinal dataset from seven waves of HRS. Estimates from unconditional quantile regressions indicate that parental dementia substantially reduces household wealth of an unmarried adult child in the upper quantiles of the wealth change distribution in the first two years after parental diagnosis. These effects are more pronounced for unmarried adult children without siblings. Further, this response is observed to persist in the subsequent time period as well. An examination of mechanisms suggests that both, losses in labor income and nursing

home expenditures, may play a role in leading to wealth declines. This paper makes two contributions: first, it focuses on a broader outcome of private cost, and second, unlike previous studies, it does not limit the analysis to adult children who are informal caregivers.

The final essay examines the cost implications of publicly provided formal care services. Medicaid's Personal Care Services (PCS) State Plan benefit is a key mechanism through which states provide personal assistance services to eligible beneficiaries. But, it is widely claimed that states are reluctant to adopt the program over fears of runaway spending. Surprisingly, there has been very little empirical work on examining the effect of the PCS State Plan benefit on Medicaid expenditures. Using aggregate state-level data from 1975 through 2009, this study finds that PCS State Plan adoption had no overall effect on Medicaid expenditures, except briefly during the early-growth years in 1980s. Further, findings suggest that states make decisions to adopt the program based on financial experiences of other adopting states. This study provides evidence consistent with the interpretation that when faced with the dilemma of balancing increased access and uncontrolled expenditures, state officials adapt the design of an entitlement benefit in an effort to make it less expensive.

In its entirety, the dissertation provides new thinking on two dominant themes in conventional long-term care research: "caregiver burden" and "woodwork effect." In particular, the results of the first and third essay question the presence of "caregiver burden" and "woodwork effect" respectively, while the third essay challenges the pervasiveness of "caregiver burden" among unmarried adult children. These findings, which in some aspect are unexpected in the context of existing literature, have important implications for policy intervention and the direction of future research efforts in this area.

Three Essays on the Supply of Long-Term Care Services to the Elderly in the U.S.

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# Table of Contents

<b>ESSAY 1: IS THERE A TRADEOFF BETWEEN PARENT CARE AND SELF CARE? .....</b>	<b>1</b>
1.1 INTRODUCTION .....	1
1.2 BACKGROUND .....	2
1.3 METHODOLOGY .....	6
1.3.1 <i>Model Specification and Estimation</i> .....	7
1.4 DATA .....	9
1.4.1 <i>Sample</i> .....	10
1.4.2 <i>Dependent Variables</i> .....	11
1.4.3 <i>Independent Variables</i> .....	14
1.5 RESULTS .....	18
1.5.1 <i>Parental Need</i> .....	19
1.5.2 <i>Wage Effects</i> .....	21
1.5.3 <i>Other Characteristics</i> .....	22
1.6 CONCLUSION .....	23
<b>ESSAY 2: HOW DOES DEMENTIA ONSET IN PARENTS INFLUENCE ADULT CHILDREN’S WEALTH? ....</b>	<b>29</b>
2.1 INTRODUCTION .....	29
2.2 BACKGROUND .....	31
2.3 MODELING THE EFFECT OF PARENTS’ HEALTH ON ADULT CHILD’S WEALTH .....	33
2.4 DATA .....	36
2.4.1 <i>Sample and Measures</i> .....	37
2.4.2 <i>Summary Statistics</i> .....	39
2.5 RESULTS .....	41
2.5.1 <i>Main Results</i> .....	41
2.5.2 <i>Robustness Check</i> .....	43
2.5.3 <i>Delayed Effects</i> .....	44
2.5.4 <i>Mechanisms</i> .....	44
2.6 CONCLUSION .....	46
<b>ESSAY 3: EFFECT OF THE PERSONAL CARE SERVICES STATE PLAN OPTION ON MEDICAID EXPENDITURES .....</b>	<b>56</b>
3.1 INTRODUCTION .....	56
3.2 BACKGROUND .....	59
3.3 LITERATURE REVIEW .....	60
3.4 METHODS .....	63
3.5 DATA .....	64
3.5.1 <i>State Medicaid Expenditures</i> .....	64
3.5.2 <i>PCS State Plan option</i> .....	65
3.5.3 <i>1915(c) waivers offering personal care</i> .....	66
3.5.4 <i>Other Control Variables</i> .....	67
3.6 RESULTS .....	69
3.6.1 <i>Effect of PCS State Plan over time</i> .....	70
3.6.2 <i>Heterogeneous behavior in PCS State Plan adoption</i> .....	73
3.7 CONCLUSION .....	75
<b>REFERENCES .....</b>	<b>86</b>
<b>VITA .....</b>	<b>94</b>

## List of Figures

<i>Figure 2-1 : Sample Selection.....</i>	<i>49</i>
<i>Figure 2-2 : Effect of Dementia Onset on Wealth for Unmarried Only Children.....</i>	<i>52</i>
<i>Figure 2-3 : Effect of Dementia Onset on Income for Unmarried Children .....</i>	<i>55</i>
<i>Figure 3-1 : PCS State Plan Adoption in the U.S. ....</i>	<i>78</i>
<i>Figure 3-2 : Cumulative Number of States with PCS State Plan.....</i>	<i>80</i>
<i>Figure 3-3 : Cumulative Number of States with PCS State Plan &amp; 1915(c) waivers that provide personal care.....</i>	<i>81</i>
<i>Figure 3-4 : Effect of PCS State Plan on Expenditures Over Time.....</i>	<i>83</i>
<i>Figure 3-5 : Cost of PCS Adoption for Non-Adopting states.....</i>	<i>85</i>



## List of Tables

<i>Table 1-1: Descriptive Statistics</i> .....	26
<i>Table 1-2 : Determinants of Time Allocation: Women</i> .....	27
<i>Table 1-3 : Determinants of Time Allocation: Men</i> .....	28
<i>Table 2-1 : Descriptive Statistics</i> .....	50
<i>Table 2-2 : Quantile Regressions of Parent's Dementia Onset and change in Unmarried Adult Child's Wealth</i> .....	51
<i>Table 2-3 : Delayed Effect Quantile Regressions of Parent's Dementia Onset and change in Unmarried Adult Child's Wealth</i> .....	53
<i>Table 2-4: Probit Regressions of Parent's Dementia Onset and Subsequent NH admission</i> .....	54
<i>Table 3-1 : Descriptive Statistics</i> .....	79
<i>Table 3-2 : Effect of PCS State Plan on Medicaid Expenditures</i> .....	82
<i>Table 3-3 : Fixed Effects Regressions with Interactions</i> .....	84

## **Essay 1: Is there a Tradeoff between Parent Care and Self Care?**

### **1.1 Introduction**

As the American population continues to age rapidly, the provision of long-term care (LTC) for older Americans becomes an increasingly urgent issue. The current system of LTC relies heavily on informal—that is, unpaid—caregivers. Informal caregivers are predominantly middle-aged females, a majority of who are employed (Alexih, Zeruld and Olearczyk, 2002). The typical care recipient, most often a parent, is also a female (Alexih, Zeruld and Olearczyk, 2002). This is mainly because women tend to live longer and often outlive their spouses. According to Donelan et al. (2002), family caregivers devote a substantial amount of time helping a relative: about one-third of caregivers report providing 21 or more hours of help per week. In addition, many caregivers provide assistance for long periods of time, with over 40 percent having provided help for at least five years (Donelan et al., 2002).

Numerous studies have examined the adverse effects of caregiving on the physical and psychological health of informal caregivers. For instance, Pinquart and Sorensen (2003) conducted a meta-analysis of 228 studies and concluded that studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among non-caregivers. However, despite the existence of a large literature on “caregiving burden,” only a few studies have specifically analyzed the relationship between caregiving and leisure-time physical activity (Vitaliano et al., 2002; Gallant and Connell, 1997; Burton et al., 1997; Lim and Taylor, 2005; King and Brassington, 1997; Scharlach et al., 1997).

Much of this work also suffers from methodological problems, including the use of non-random samples, control groups that are matched only on the basis of a few observables, and

poorly-specified empirical models. There is also limited evidence in the literature on where the time spent in care comes from: it does not appear to have been diverted from home production time, and there is little agreement on whether it comes from time that was previously devoted to work.

In this paper, we examine the relationship between parental caregiving and physical activity from a time-allocation perspective. Specifically, we ask whether a tradeoff exists between hours spent in informal care and the frequency of leisure-time physical activity. An empirical model that specifies a jointly-estimated system of four equations using pooled data from the Health and Retirement Study (HRS) is used to answer this question. Given the current level and projected growth of informal care provision, this is an important step towards designing effective caregiver support programs.

The rest of the paper proceeds as follows. Section 1.2 describes the literature and motivations for the study. Section 1.3 discusses the methodology while Section 1.4 describes the data and sample. Section 1.5 presents the results and Section 1.6 concludes.

## **1.2 Background**

Physical activity relates to informal caregiving in at least two ways (Etkin et al., 2008). First, as a coping mechanism, it has the potential to buffer the impact of stressors (Howard, Cunningham and Rechnitzer, 1984). That is, if caregivers are engaging in physical activity, then the resultant stress caused by behavior and memory problems of care recipients might be better tolerated. Second, from a time allocation perspective, more time in care provision might mean less time for physical activity (Castro et al, 2002).

Though the role of physical activity as a mediator of stress has been widely demonstrated (Boise, Congleton and Schmall, 2000; Castro et al., 2002), only a limited number of studies have

examined the impact of caregiving on physical activity. A few of these studies find that elderly caregivers to a spouse reported doing less exercise (Vitaliano et al., 2002), decreasing physical activity since becoming caregivers (Gallant and Connell, 1997), and having less time for exercise than same-aged married non-caregivers (Burton et al., 1997; Vitaliano et al., 2002). Other studies find no difference between caregivers and non-caregivers on rates of physical activity (Lim and Taylor, 2005) or weekly exercise (King and Brassington, 1997; Scharlach et al., 1997).

Not only is a consensus on this topic absent, the methodology employed in many of these studies raises serious internal validity concerns. For instance, while some studies do not include a control group for non-caregivers (Gallant and Connell, 1997), others match caregivers with non-caregivers only on the basis of a few observables, usually age and gender (Vitaliano et al., 2002, Burton et al., 1997). Finally, studies (e.g., Lim and Taylor, 2005; Scharlach et al., 1997) also fail to recognize that because caregiving and physical activity are two kinds of time-uses decided by the same person, it is inappropriate to model one decision as a function of the other; instead, the two should be viewed as jointly chosen outcomes.

When discussing the impact of caregiving on physical activity, it is important to acknowledge recent evidence (termed the “healthy caregiver hypothesis”) suggesting that as high intensity care responsibilities increase, caregivers achieve better physical functioning because such responsibilities themselves may include a large physical component (Fredman et al., 2006; Bertrand, Fredman and Saczynski, 2006). The physical activity inherent in performing certain care tasks may help to improve caregivers’ physical and cognitive health. While potentially true, “the healthy caregiver hypothesis” does not preclude the need for leisure-time physical activity. Physical activity performed as a part of the caregiving process may not act as a mediator of caregiving stress and to the extent that stress acts as a risk factor to a caregiver’s mental and

physical health, leisure-time physical activity has an important role to play.

In recognition of the overall health benefits conferred by physical activity, the Centers for Disease Control (CDC) (2008) has issued guidelines relating to minimum physical activity levels for children, adults and older adults. Specifically, according to the CDC, to achieve important health benefit, adults need at least 30 minutes of moderate physical activity (i.e., brisk walking) five days a week as well as muscle strengthening activities on two or more days a week. Alternatively, adults could also do 20 minutes of vigorous physical activity (i.e., jogging or running) three days a week in addition to muscle strengthening activities on two or more days a week to achieve the same benefits.

If increased care responsibilities are associated with a reduced frequency of physical activity such that the probability that individuals engage in physical activity “multiple days a week” is substantially reduced, then existing caregiver support programs may need to be adjusted to include components that promote physical activity. Currently, the National Family Caregiver Support Program (NFCSP) is the key government program that provides assistance to family caregivers. With an overall budget of \$154 million in FY 2010 (The U.S. Administration on Aging, Office of Budget & Finance, 2011), the main components included in the NFCSP are provision of counseling, support groups and respite care (Administration on Aging, 2004). If caregivers’ physical activity levels are falling below the recommended guidelines, the NFCSP might usefully be extended to include strategies that promote physical activity among caregivers. For example, a telephone-supervised, home-based, physical activity regimen has been demonstrated in past research to be one such strategy for increasing physical activity in the caregiving population (King and Brassington, 1997).

In addition to the policy context discussed above, a key motivation for this study relates to

limitations of previous literature on caregiving and time-use. Given the time demands associated with caregiving, researchers have attempted to address the tradeoff between time spent in care activities and time spent in other activities. This work, however, has largely concentrated on estimating the causal relationship between caregiving and employment. Initial analyses were generally based on cross-sectional models of labor market participation and parental care (Muurinen 1986; Stone and Short 1990; White-Means 1992) but these studies failed to consider the endogeneity problem that arises when estimating the causal effect of informal care on work. Specifically, reduced-form estimates are prone to selection bias if adult children who have poor labor market prospects are also more likely to take on the caregiving role.

Newer research has tried to address this endogeneity problem in a variety of ways, but, results from these studies have been mixed. Wolf and Soldo (1994) estimated a simultaneous equations model and found no reduction in married women's employment or hours of work due to caregiving; Ettner (1995), in contrast, found that women's labor supply is significantly reduced by co-residence with an elderly disabled parent, primarily because of withdrawal from the labor market. She used predictors of parents' health status (education, age and marital status) and the number of siblings as instrumental variables for co-residence in a two-stage estimation. In a recent paper, Van Houtven, Coe and Skira (2013) examine both intensive and extensive margins of labor market participation. They control for time-invariant individual heterogeneity via fixed effects. They also control for any remaining endogeneity by using measures of parental health as instruments for informal caregiving. They find that care provision does not affect a woman's probability of working. They also find that caregiving is associated with relatively moderate reduction in work hours, with large decreases concentrated mostly among high-intensity caregivers.

The lack of consistent, conclusive evidence that informal care and labor supply decisions are negatively correlated has led some researchers to speculate that a time tradeoff may come from activities other than work, such as housework or leisure (Wolf and Soldo 1994). Couch, Daly and Wolf (1999) considered four demands on household time and money resources: time spent working, time spent providing care to elderly parents, time spent performing household work, and monetary transfers to non-coresident elderly parents. Their findings indicate that parental factors associated with increased time transfers to parents do not induce reductions in either labor market or housework time.

The absence of negative correlations among competing time-uses suggests that there is scope to further disaggregate time spent in leisure activities into other “productive” uses of time such as physical activity. Because there are only 24 hours in a day, time for care must be found somewhere. This paper attempts to determine whether care time is subtracted from time that would have otherwise been devoted to activities relating to investment in one’s own health, specifically to exercise.

### **1.3 Methodology**

Time allocation studies are grounded in the New Home Economics models of the 1960s. These models view families as engaging in production of goods much like a firm (Becker, 1965). Families convert time, material resource inputs, and purchased services into abstract household goods. In particular, Becker’s approach recognized the importance of time allocation in the production of household goods.

In simple models, two activities fully accounted for time available: time in the labor market and time in leisure. Gronau (1977) expanded the traditional two-dimensional time allocation model to three uses of time: market work, leisure and home production. These categories are

mutually exclusive and exhaustive such that when two of the three categories are determined, the third is implied. The optimal time allocation by each individual depends on the value of time in each activity (or, the opportunity cost of that time), as well as the preferences of the individual. Thus an individual's time allocation decisions are not only simultaneously determined but are also dependent on tastes and other unobserved variables that may be correlated across outcomes (Couch, Daly and Wolf, 1999).

Following Gronau's work, Kooreman and Kapteyn (1987) modeled the allocation of time by couples between market work and a variety of non-market activities, including home production, child care, hobbies and personal care. Although their model takes account of multiple time uses, it does not allow for cross-equation correlations between them.

More recently, in studying mother's time use, Kimmel and Connelly (2007) further expand the Gronau triad into five aggregated uses of time: (paid) market work, unpaid housework, child care, leisure and other (including sleep, personal care time, education, and so on). Their results show that mother's caregiving time increases with the number of children, decreases with age of the child and increases with price of child care.

### **1.3.1 Model Specification and Estimation**

As discussed above, we assume that households are productive units whose primary resources are time and money. Because caregiving and physical activity are two kinds of time use, it is theoretically indefensible to model one decision as a function of the other. Such an equation would not have a precise *ceteris paribus* interpretation because the amount of time devoted to both care and physical activity is decided by the same individual (Wooldridge, 2002). The interrelationships among time uses suggest that all factors associated with the value of time spent in any one activity influence decisions about all other time allocations. In this case, one



cannot hold time spent in caregiving fixed, because anything that influences the decision on how much time to spend on physical activity, simultaneously influences the decision regarding care hours and all other uses of time. This also rules out the existence of an exclusion variable that influences one category of time allocation without affecting all other types of time uses.

Therefore, it is appropriate to model these time-use outcomes jointly. The model used in this paper is a system of four time-use equations where each individual's decisions about time-allocation are jointly determined. The outcomes in this reduced-form model are time spent in caregiving, the frequency of two types of physical activity (moderate and vigorous), and time spent in paid employment. Because the four time uses pertain to the same individual, error terms are assumed to be correlated across all equations. The four equations take the form:

$$t_j = \beta_{0j} + \beta_j'X + \varepsilon_j \quad \text{for } j = \text{care, paid employment; and}$$

$$f_p = \beta_{0p} + \beta_p'X + \varepsilon_p \quad \text{for } p = \text{moderate and vigorous physical activity.}$$

Here,  $X$  is an array of explanatory variables common to all equations.

These four equations are estimated jointly through a mixed-process model that included an “ordered Probit with known thresholds” (Lillard and Panis, 2003) for care hours<sup>1</sup>, two Probits for the physical-activity outcomes, and a Tobit for work hours. The joint estimation was done using the statistical software aML (Lillard and Panis, 2003). To account for clustering in the pooled data, a time-invariant, person-level random effect was included in each equation with correlations at the person-level across equations.

---

<sup>1</sup> “Ordered Probit with known thresholds” is a generalized censored regression also known as “interval regression.”

## 1.4 Data

The analysis uses data from four waves (2004-2010) of the Health and Retirement Study (HRS). The HRS is a nationally representative, biannual survey of the near elderly in the United States (Juster and Suzman, 1995). Persons aged 51-61 entered the sample initially, thus making their parents prime candidates to be care recipients. The HRS collects detailed information not only about the respondents and their spouses, but also important information about their parents and siblings. We use only four waves because questions on the frequency of various types of physical activity were asked for the first time in 2004.

While the HRS employs the “recall” method to collect data on various time-uses, it is generally noted that time diaries (such as those collected by the American Time-Use Survey – ATUS) are the gold standard for measurement of time-use, mainly because they collect time allocation data in a structured way and involve a relatively short recall period (Van den Berg and Spauwen, 2006). This gold standard is, however, not universally accepted. According to Bittman et al. (2004), time diaries fail to capture the real burden of caregiving and therefore can potentially underestimate time inputs. Self-reported hours of care may reflect supervisory time, i.e., a need to be “on call.” Diaries, on the other hand, are designed primarily to record activities, and being on call seldom shows up as an activity (Budig and Folbre, 2004).

An additional complication is that care activity may be embedded in and absorbed into normal domestic activity (Wolf, 2004). For example, in time diaries, joint production of a meal to be consumed by both the caregiver and the care recipient is already assigned a domestic activity code and does not register as a specific activity associated with caregiving. In evaluating the accuracy of the recall method for measuring time spent in informal care, Van den Berg and Spauwen (2006) conclude that if one assumes that respondents take into account joint production

when completing the recall questionnaire, the recall method is a valid instrument to measure time spent on the provision of informal care.

For these reasons and due to the fact that the ATUS does not collect data on parental need factors (which tend to provide key exogenous variation for time spent in care tasks), we use the HRS for this analysis. Any measurement error in reporting time-use due to recall or social desirability bias will be present in the dependent variables, which has relatively less serious consequences (Bound, Brown and Mathiowetz, 2001).

#### **1.4.1 Sample**

We focus exclusively on care provided by adult children to parents because parental caregiving is the most common care scenario and is also the most relevant given the middle-age profile of the HRS respondents. In contrast, spousal caregiving is a commonly reported care situation for those over 75 years of age.

We restrict the sample to those respondents who have at the minimum, one parent alive, or a parent in-law alive or those who have experienced the recent death of either a parent or an in-law. Respondents who have experienced the death of a parent or a parent in-law since the time of the last interview are included because a substantial amount of care is provided at the end-of-life stage. Further, to ensure that respondents were of working age—i.e., those for whom labor market participation is most relevant—we restricted the sample to individuals below age 65.

These sample selection criteria led to a total of 8,998 observations. After deleting observations with missing values (3.8%)<sup>2</sup>, a final sample size of 8,658 was achieved. Of these, 3,892 (45%) are women and 4,766 (55%) are men. Individuals appear in the pooled analysis file

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<sup>2</sup> A comparison of means between the original sample (N=8,998) and the final sample (N=8,658) revealed no evidence of any systematic bias due to missing data.

from one to four times, depending on how often they meet the inclusion criteria mentioned above.

### 1.4.2 Dependent Variables

The four dependent variables (Table 1-1) used in this analysis are hours of care, frequency of moderate and vigorous physical activity and hours spent in paid employment. Hours of care is only asked if the respondent provided at least 100 hours of care in assisting parents with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). ADLs include self-care activities such as eating, bathing, dressing, transfers and walking. The survey question is worded as follows: *“Did you spend a total of 100 or more hours [since last interview, in the last two years] helping your (deceased) [parents/in-laws] with basic personal activities like dressing, eating, and bathing?”* Unlike ADLs, IADLs are not necessary for fundamental functioning, but they facilitate independent living in a community. Similar to the question on ADLs, for IADLs the HRS asks *“Did you spend a total of 100 or more hours [since last interview] helping your (deceased) [parents/in-laws] with other things such as household chores, errands, transportation, etc.?”* If the answer either of these questions is “yes” then the respondent is asked: *“Roughly how many hours did you spend [since last interview, in the last two years] giving such assistance to your parents/in-laws?”* This question is repeated, separately, for the spouse.

We used a combined measure of caregiving (personal care and chores) as the dependent variable in the first equation. That is, the effective time (over two years) spent caring for parents is defined as the sum of time spent helping parents with basic personal needs and time spent helping parents with household chores. While some studies separate ADL and IADL care to account for heterogeneity of response based on the type of care, from a time allocation

perspective it is appropriate to combine the two because ADL care is frequently accompanied by IADL care, thus providing a more comprehensive measure of the total amount of time spent in informal care.

As discussed in the background section, both ADL and IADL caregiving tasks may involve physical activity. It is important to acknowledge that there is likely to be a tremendous amount of heterogeneity in the degree of physical exertion involved in care tasks across individuals. However, from an empirical perspective, we are unable to take this heterogeneity into account because our data do not provide this level of detail on the nature of individual care scenarios.

A sizeable proportion of the respondents who said “yes” to providing more than 100 hours of ADL answered “don’t know” to the subsequent question on the actual number of care hours. This may reflect the difficulty of recalling the intensity of care efforts as much as two years in the past. These respondents were then asked a follow-up question that asked them to choose from among three possible ranges of care hours: 0-199 hours; 200-499 hours; and 500-5000 hours.<sup>3</sup>

Table 1-1 presents summary statistics for “hours of care” for women and men. Interval-coded values appear as “lower” and “upper” bounds, respectively<sup>4</sup>. For those that specified a value for their care hours, the same value appears as a lower and upper bound. The unconditional (i.e., including zeros) mean for the lower bound of care hours for women is around 198 hours over a two year time period, while the same for the upper bound is 684 hours. Not surprisingly,

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<sup>3</sup> The RAND HRS family data files do provide an imputed scalar value for respondents who reported an interval measure for care hours. However, concerns regarding an imputed value’s accuracy become key given the wide range and two-year time period of the interval. For this reason, we model the interval range as the dependent variable in the care-hours equation. As compared to imputed data, using intervals leads to larger variances, thus yielding tests of significance that are generally more conservative.

<sup>4</sup> Observations reporting zero care hours are coded as falling into the  $-\infty, 0$  interval as “ordered Probit with known thresholds” is a generalized Tobit estimation.

these numbers are much higher for women than men, suggesting that women provide more hours of care, in general. Also, as expected, for caregivers<sup>5</sup> (42% among women and 36% among men), the mean values for both the lower and upper bounds are considerably higher than those for the entire sample of women and men (unconditional means).

With regard to the frequency of different types of physical activity, the HRS asks respondents how often they engage in three kinds of physical activity – mild, moderate and vigorous. Because the CDC guidelines are limited to only moderate and vigorous physical activity, we don't include mild physical activity in our analysis.

For vigorous physical activity, the HRS asks, *“How often do you take part in sports or activities that are vigorous such as running or jogging, swimming, cycling, aerobic or a gym workout?”* Similarly, for moderate physical activity, the HRS asks respondents, *“How often do you take part in sports or activities that are moderately energetic such as, brisk walking, gardening, cleaning the car, dancing, floor or stretching exercises?”* The response categories for both questions are “hardly ever or never,” “one to three times a month,” “once a week,” and “more than once a week/every day.” Given the inherently physical nature of many care tasks, there might be concern that some respondents think of caregiving as physical activity. However, because the description of the questions contain explicit examples, it is unlikely that individuals included care tasks in their responses on physical activity participation.

In a further effort to keep the analysis relevant to CDC guidelines, we created dichotomous variables expressing physical activity frequency as either “multiple times a week” or “less than multiple times a week” for both moderate and vigorous physical activity. Table 1-1 demonstrates that approximately 56% of women and 60% of men report doing moderate physical

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<sup>5</sup> Those with positive ADL or IADL care hours

activity “multiple times a week.” In contrast, only 25% of women and 33% of men report doing vigorous physical activity “multiple times a week.” It is not surprising that a higher percentage of men and women frequently perform moderate physical activity. In addition to being physically more strenuous, vigorous activity also entails a higher investment on the part of an individual. For example, while one can do stretching exercises (an example of moderate physical activity) in the confines of his/her residence, an aerobic workout or a swim (examples of vigorous physical activity) will entail a gym membership, special attire and other sports gear. Thus, even from a non-physical perspective, engaging in moderate physical activity is relatively more feasible. In general, the descriptive statistics also show that men are likely to engage in both types of physical activity more frequently than women.

The hours of work variable is taken from the RAND HRS (2011) data files. It is the sum of the typical number of hours per week the respondent works at the main job and at a secondary job, if any. If the respondent is not working, the hours of work are coded to zero. Table 1-1 shows substantial differences between the unconditional and conditional means for employment hours. This is because 39% of women and 29% of men do not work. When everyone is included, the mean hours spent in paid employment are about 23 hours per week for women and 32 hours per week for men; when considering only those who are employed, the mean hours spent in paid employment are around 38 hours per week for women and 45 hours per week for men.

### **1.4.3 Independent Variables**

The explanatory variables (summarized in Table 1-1) include characteristics of parental health and need,  $P_i$ , the respondent’s individual and demographic characteristics,  $Z_i$ , characteristics of respondent’s health,  $H_i$ , and characteristics of the respondent’s household,  $D_i$ .

The vector  $P_i$  represents the key explanatory variables, those that measure parental health status. Separate indicators for mother, father, mother in-law and father in-law are included in the regression analyses. As parental health declines, hours of care are hypothesized to increase and frequency of physical activity is expected to decrease. It is also expected that as parental health declines, hours of work should also decrease. These variables include a dummy variable for whether the parent can be left alone for an hour (coded as 1 if the parent *cannot* be left alone for an hour) and another indicating whether the parent has ADL needs. Almost all respondents who said “yes” to whether parents cannot be left alone for an hour also reported parents having ADL needs. To avoid overlap, the measure for whether parent has ADL need excludes those who said “yes” to whether parents cannot be left alone for an hour; thus the “ADL needs” variable represents needs beyond any revealed by the “cannot be left alone” variable.

We also control for parents’ marital status. If parents are married (whether to each other or otherwise), then the adult child is less likely to provide care due to the availability of an alternate caregiver, the parent’s spouse. The three “need” indicators discussed above (including parent’s marital status) pertain only to parents alive at the time of the interview.

Finally, for those individuals whose parents died recently (i.e., since the last interview), we include two variables that indicate whether the parent died due to an illness lasting three months or more; and whether the parent died without an illness lasting three months or more. Because the period before death is likely to characterize a significant need for care regardless of cause, we expect both variables to positively predict care hours. That said, we hypothesize that death due to an illness would lead to a higher increase in care hours as compared to death without an illness. Similarly, we expect that death with an illness would lead to a larger decrease in the frequency of physical activity and hours of work (if any) as compared to death without an



illness. Disaggregating parent's recent death by cause allows us to examine how different levels of parental need influence various time allocation decisions.

As depicted in Table 1-1, almost 60% of the women have a living mother, while only 24% have a living father. Though the numbers are smaller for men, the trend is similar. Not only are more mothers alive than fathers, mothers are also more likely to require care: while 7% of the women report that their mothers "cannot be left alone for an hour," only 2% of the women report that their fathers "cannot be left alone for an hour." Similarly, even among men, while 7% report their mothers have "ADL needs", only 3% report that their fathers have "ADL needs".

The vector  $Z_i$  includes the respondent's age, education, race, marital status, number of siblings (number of sisters and number of brothers separately), the natural log of hourly wage and wealth. The mean age for women and men is 58 and 59 years, respectively. Approximately 78% of women and 84% of men are white. Further, a large majority of both men and women are married or living together.

As discussed above, for a large percentage of individuals in the sample—those not presently working—the hourly wage rate is missing. Because this is suggestive of selection bias, we predict wages for the entire sample (men and women together) using a two-step, Heckman estimation procedure (results available on request). Variables included in the reduced form employment equation that are not included in the log-wage equation include measures of parental need, spousal need, respondent health and marital status. Age, education, experience, a second order term for experience and gender are included in the wage equation<sup>6</sup>.

In the first stage estimation, several of the identifying variables, including spousal need and some measures of parental health are significant predictors of employment. In addition, the

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<sup>6</sup> To check for wage penalties, we included parental need variables in one specification of the wage equation. We found no statistically significant evidence of reduced wages as a result of poor parental health.

F-test of the wage equation estimation is also significant at 0.01 level, indicating that all the included variables contribute to the prediction of wage levels. After the second stage, selectivity corrected, predicted log wage is imputed for all respondents. As expected, the mean predicted log wage is higher for men than women.

We also control for non-housing financial wealth. This includes the sum of appropriate wealth components (such as savings, checking, mutual funds, stocks, bonds, and Treasury Bills) minus debt. This measure is taken from the RAND version of the HRS. Because the RAND version of the HRS imputes values for those who either gave no response or an interval response, there were no missing observations.

The vector  $H_i$  includes plausibly exogenous variables that determine a respondent's health status. Health status is likely to have an effect on how the respondent decides to allocate his or her time.  $H_i$  consists of two indicator variables: whether the respondent ever smoked (specifically, smoked 100 cigarettes or more in their lifetime), and a lagged measure (from the previous wave of the HRS) of the respondent's Body Mass Index (BMI). Other health status variables in the HRS, for example self-reported physical and mental health status, are not included because they may be simultaneously determined along with the dependent variables and thus may be subject to endogeneity bias.

Finally, household characteristics,  $D_i$ , include indicator variables for spouse's health, the number of co-resident children under 18 years of age, spouse's age, number of spouse's siblings and spouse's work experience. Spousal health characteristics and the number of co-resident children are intended to capture intra-household demands on an individual's time. With deteriorating spousal health, we expect that an individual's time allocation in parent care, physical activity and work will compete with his/her time allocation in spousal care. We use

spouse's ADL needs (as measured by the sum of five possible ADL limitations) to control for spousal health. Similarly, time allocation in any non-childcare related activity may also decrease as the number of children under 18 years of age in the household increase.

It is important to recognize that among married individuals, the decision regarding time transfers to parents or parents-in-law is taken in a household context. For example, spousal time allocation in parental care is a key predictor of the respondent's time allocation in the same task. From a modelling perspective, however, explicitly controlling for the amount of time the spouse spends in various activities creates an endogeneity problem. Therefore, in order to represent this intra-household decision making context, we include certain exogenous variables that are likely to directly influence spouse's time allocation decisions. These variables include spouse's age, spouse's work experience and spouse's siblings (number of sisters and number of brothers separately). The control for spousal health described above is an additional control for this intra-household decision making context. Note, for those individuals who don't have a spouse, these variables are coded to zero.

## **1.5 Results**

Table 1-2 and Table 1-3 (for women and men respectively) present the estimated marginal effects on the unconditional expected value of hours spent in caregiving, predicted probabilities of engaging in moderate and vigorous physical activity multiple times a week, and unconditional expected value of hours spent in employment. Marginal effects are slopes for continuous explanatory variables (e.g., wage rates) or discrete changes in the outcome variable for dummy-coded explanatory variables (e.g., mom has ADL needs). All standard errors are Huber-corrected.

### 1.5.1 Parental Need

As expected, care hours respond positively to almost all parental need characteristics. Having a mother or father who cannot be left alone for one hour, or requires help in completing ADL tasks all lead to significant increases in care hours. For instance, among women, having a mother who cannot be left alone for an hour increases average care hours by 214 hours over a two-year period. Among men, having a father who cannot be left alone for an hour increases average care hours by 114 hours over a two year period. Further, as expected, experiencing a recent death of a parent due to an illness leads to a greater increase in care hours as compared to a recent death of a parent without an illness. For example, among women, having had a mother who died recently with an illness increases care hours by 265 hours over a two year period, but in contrast, having had a mother who died without an illness increases care hours by a lesser amount -- 187 hours. We find similar results among men.

The results suggest that women's increases in time allocated to caregiving in response to parental needs are larger than men's. In addition, as demonstrated in the literature previously (Lee, 1993), there is evidence of same-gender preferences: women are likely to increase care hours more in response to their mother's physical needs than to their father's. Similarly, men are likely to increase their care hours more in respect to father's health needs as opposed to the mother's.

Overall, there is limited support for the existence of a time conflict between hours of care and frequency of physical exercise. The results demonstrate that even though most parental need characteristics positively predict hours of care; they do not comprehensively predict compensatory decreases in the frequency of physical activity.

Among women, having a father who needs help with ADL tasks increased the number of

care hours over a two year period by 161 hours and reduced the frequency of engaging in vigorous physical activity multiple times a week by 10%. There is some indication that having a father who died without an illness – a type of parental need that is relatively less severe due to its presumably shorter length – led to an increase in the probability of frequent participation in physical activity. However, it is not entirely clear how having had a father who died without an illness affects care hours – for both men and women, this variable increases care hours by only a very small and statistically insignificant number. Finally, among women, having a mother who is married increased the probability of engaging in moderate physical activity multiple times a week by 10%. The mother's marital status negatively predicts care hours, though again, the estimate is not statistically significant. None of the other parental need variables predicted a statically significant tradeoff between care and physical activity among either men or women.

Interestingly, among men, the estimated correlations of unobservables between time spent in caregiving and the two types of physical activity are positive (see “Rho – Care” bottom of Table 1-3). This suggests that among men, after controlling for parental need and other variables, unobservable factors influence time allocation in caregiving and physical activity in the same direction. Some of these unobservables may include self-efficacy, beliefs regarding quality of life and health, and so on. Further, it is also likely that better mental health, which we don't include in the regressions as it is almost certainly endogenous, positively predicts both the amount of care time and frequency of physical activity. The estimated correlations between care and physical activity are positive, but small and statistically insignificant among women.

Focusing on another type of time conflict, that between care hours and work hours, the results demonstrate that among men, having a mother who cannot be left alone for an hour negatively influences hours of work. Specifically, having a mother with intensive care needs

reduces average work hours by close to four hours per week. The corresponding result for women is also negative but statistically insignificant. Similarly, facing a non-illness related death of a mother in the last two years is associated with an increase in work hours for both men and women. As discussed previously, the literature has yet to reach a general agreement on the effect of informal care provision on labor force participation. Our results are somewhat consistent with recent evidence from the U.S. suggesting that personal care assistance reduces the probability of working among men and leads women who are working to reduce work hours (Van Houtven, Coe and Skira, 2013). It is possible that we achieve imprecise estimates for women because almost 40% of the women in our sample do not work.

With regard to error correlations, among both women and men, there is a negative and statistically significant correlation between care hours and work hours. In this case, the unobservable factors provide a clear indication of a conflict between two the competing uses of time.

### **1.5.2 Wage Effects**

Theory predicts that higher wages should lead to an increase in hours of work. In addition, as the opportunity cost of time increases, hours of care should decline. The results show that an increase in predicted log wage leads to only small decreases in care hours for both men and women. Further, the results are statistically insignificant in both cases. Conclusions from recent literature can help explain this result. According to Nizalova (2012), wage elasticity estimates of informal care are subject to an omitted variable bias and thus biased upward. For example, some people may be more productive in everything they do, which is difficult to control for with a conventional set of variables available to researchers. Therefore, these people would provide more care, but also would be rewarded in the market with higher wages. In addition, the price of

formal care is likely to be higher for people living in high-wage areas, and a high price of formal care might mean more hours of informal care (if formal and informal care are substitutes for each other). Thus, failure to control for price of formal care would further result in an upward biased estimate of wage effect on informal caregiver time.

### **1.5.3 Other Characteristics**

While some previous research has suggested that African Americans express stronger kinship support than whites (Dilworth-Anderson et al., 2005), the overall evidence on racial differences in caregiving has been mixed. For instance, Janevic and Connell (2001) conclude that minority groups may not have more available support than whites. In addition, prior research has also found that Black elders receive more informal help mainly because Blacks are more disabled (Li and Fries, 2005). Nevertheless, we find that even after controlling for parental need, being black (as opposed to white) increases care hours among both men and women (although the result is statistically significant only for men).

Among women, being black decreases the frequency of moderate physical activity by about 9%. Each additional sister reduces average care hours for both men (by about nine hours) and women (by about 24 hours). Similarly, among women, each additional sister-in-law reduces women's average care hours by about 14 hours. These variables are most likely picking up the presence of substitute caregivers.

Interestingly, indicators of health risk factors (smoking history and lagged BMI) do not significantly predict care hours for either men or women. However, as expected, each additional unit of lagged BMI is associated with decreases in the probability of engaging in both types of physical activity multiple times a week for both men and women. BMI is also associated with decreased work hours among women.

Among women, each additional ADL need of the spouse leads to a 22 hour reduction in care hours to parents. This suggests that time allocated to caring for spouse competes with time allocated to caring for parents. Another control for intra-household demands on the respondent's time is the number of children in the household. Among women, there is no effect of each additional child in the household on time allocation to parents. Interestingly, among men, each additional child leads to a small but statistically significant decrease in care hours to parents. Previous literature on the phenomenon of "sandwich generation" has found very limited evidence of a competition for assistance between children and older parents (Grundy and Henretta, 2006). It is possible that men are responding to their spouse's time allocation to parents by taking on more responsibility for child-care. However, this is only a speculation as empirical research on this topic has focused almost exclusively on women (DeRigne and Ferrante, 2012).

## **1.6 Conclusion**

Caregiving for family members has often been described as a 36-hour day. This notion has motivated researchers to ask the following question: If family members are allocating their time to provide care, what other productive uses of their time are they giving up? In this paper, we examined whether, from a time allocation perspective, a conflict exists between care hours and frequency of leisure-time physical activity. If such a tradeoff is present and if it induces a decrease in physical activity to levels below minimum guidelines set forth by the CDC, then the promotion of physical activity might become a goal of publicly-supported programs such as the NFCSP.

In our joint model of time use, parental factors associated with increased allocation of time to parents do not appear to strongly induce corresponding reductions in the frequency of physical activity. Further, unobserved factors influencing time transfers to parents and frequency of



physical activity—factors collectively represented by the regression error terms—were positively correlated across equations, at least among men. This positive correlation indicates that net of measured covariates, individuals who are motivated to provide care also have a taste for engaging in physical activity. Put another way, these two types of time-allocation decisions appear to be complements rather than substitutes. It may be the case that busy, active individuals are those most likely to take on caregiver tasks, but that they simply add those tasks to an already-busy schedule, contributing to the “36-hour day” image.

In the previous section, we provided a few examples of unobservable factors that might explain this positive correlation. In addition to those factors, it is possible that the variation in the time units (within the HRS) for measuring each type of activity—biannually for care hours, weekly for exercise and work hours—could have led to this result. Because care hours are measured over such a long interval, estimates could potentially be biased downwards. That is, over a long time period (such as two years) individuals are likely to make adjustments to accommodate potential time-allocation conflicts. Alternatively, it is probable that if one had daily measures on time spent in various activities (such as from time diary data), the results would demonstrate large negative tradeoffs. In a very short time interval, using one’s time in any given way tends, almost mechanically, to “crowd out” other potential time uses. However, such results might overstate the effects if these time conflicts are smoothed over a two-year period. Therefore, the time-period over which to examine these conflicts remains an open question, one that has key implications for any policy intervention in this area.

The empirical results of this paper are suggestive of a tradeoff between caregiving and work hours. Even after controlling for parental need, predicted log wage and other variables, the error correlations show a statistically significant, negative correlation between care time and paid

work for both men and women, indicating that time spent in caring competes with time in the labor market. Also, among men, having a mother who cannot be left alone for an hour (one of the more severe need categories) reduces weekly work hours by approximately four hours.

To conclude, we found that increases in caregiving hours primarily appear to be in response to the severity of parental health needs. There was limited evidence that parental need factors were also associated with a decreasing frequency of physical activity. An extension of this work would be to further disaggregate leisure hours (into sleep, recreation, and family time) to more comprehensively answer the question: where do care hours come from?

Table 1-1: Descriptive Statistics

	Females		Males	
<b>Sample Size</b>	3,892		4,766	
<b>A. Dependent Variables</b>	Mean	S.D	Mean	S.D
Upper Bound Care Hours, unconditional	683.81	2021.56	365.01	1403.10
Lower Bound Care Hours, unconditional	197.48	624.56	108.36	387.83
Upper Bound Care Hours, conditional	1625.78	2861.34	1013.77	2193.57
Lower Bound Care Hours, conditional	469.52	920.96	300.96	599.93
Prevalence of caregiving (%)	42%		36%	
Moderate exercise - multiple times a week (%)	56%		60%	
Vigorous exercise - multiple times a week (%)	25%		33%	
Work Hours, unconditional (weekly)	23.07	21.66	31.63	23.81
Work Hours, conditional (weekly)	37.87	14.47	44.63	14.82
<b>B. Explanatory Variables</b>	Mean	S.D	Mean	S.D
Mother is alive (%)	0.59	0.49	0.48	0.50
Mother cannot be left alone for an hour (%)	0.07	0.26	0.05	0.22
Mother needs ADL care (%)	0.09	0.28	0.07	0.26
Mother died in last two years with an illness (%)	0.07	0.25	0.05	0.22
Mother died in last two years without an illness (%)	0.02	0.15	0.02	0.14
Mother is married (%)	0.15	0.36	0.13	0.34
Father is alive (%)	0.24	0.43	0.21	0.41
Father cannot be left alone for an hour (%)	0.02	0.14	0.02	0.13
Father needs ADL care (%)	0.03	0.18	0.03	0.17
Father died in last two years with an illness (%)	0.04	0.20	0.03	0.17
Father died in last two years without an illness (%)	0.01	0.11	0.01	0.11
Father is married (%)	0.15	0.36	0.14	0.35
Age/100	0.58	0.03	0.59	0.03
Race: white (%)	0.78	0.41	0.84	0.37
Race: black (%)	0.17	0.38	0.12	0.33
Race: other (%)	0.04	0.21	0.04	0.20
Married/partnered (%)	0.71	0.46	0.87	0.33
Predicted Log Wage	2.88	0.31	3.17	0.30
Not Working (%)	0.39	0.49	0.29	0.45
Net Financial Wealth (in thousands)	94.14	308.23	117.28	547.91
Education: HS dropout (%)	0.11	0.31	0.12	0.33
Education HS Grad (%)	0.34	0.47	0.28	0.45
Education: Some college (%)	0.29	0.45	0.27	0.44
Education: College Plus (%)	0.26	0.44	0.33	0.47
Number of Sisters	1.71	1.58	1.53	1.47
Ever smoked 100 cigarettes (%)	0.48	0.50	0.64	0.48
Lagged BMI	28.53	6.48	28.54	4.85
Spouse's ADL needs	0.11	0.49	0.12	0.55
Spouse's age	41.43	27.18	47.91	19.06
Spouse's work experience	25.86	18.71	23.14	14.17
Number of Spouse's sisters	1.08	1.40	1.48	1.59

Table 1-2 : Determinants of Time Allocation: Women

	Care	Care (dy/dx)	Mod.	Mod. (dy/dx)	Vig.	Vig. (dy/dx)	Work	Work (dy/dx)
Constant	627.83 (461.35)		0.48 (0.99)		0.09 (1.21)		-190.00** (23.85)	
Mom not left alone	334.69*** (66.61)	214.36	0.10 (0.12)	0.03	0.23 (0.14)	0.05	-2.40 (1.90)	-1.59
Mom has ADL needs	405.96*** (90.34)	264.85	0.20 (0.10)	0.06	0.10 (0.12)	0.02	-1.68 (1.61)	-1.12
Dad not left alone	199.23* (84.01)	122.85	0.10 (0.22)	0.03	-0.19 (0.25)	-0.04	-0.09 (3.39)	-0.06
Dad has ADL needs	257.11** (82.52)	161.72	0.32 (0.17)	0.09	-0.54** (0.20)	-0.10	0.47 (3.15)	0.32
Mom died with illness	404.19*** (65.84)	264.96	0.04 (0.13)	0.01	0.01 (0.15)	0.00	0.75 (1.78)	0.51
Mom died w/o illness	293.41*** (88.25)	187.45	0.15 (0.20)	0.04	-0.10 (0.24)	-0.02	4.82 (2.66)	3.39
Dad died with illness	58.56 (46.03)	34.00	0.11 (0.14)	0.03	0.03 (0.17)	0.01	1.97 (1.78)	1.35
Dad died w/o illness	105.56 (76.94)	62.67	0.03 (0.27)	0.01	0.64* (0.29)	0.15	-0.26 (4.33)	-0.18
Mom married	-70.50 (44.55)	-38.98	0.36** (0.14)	0.10	0.16 (0.16)	0.03	-0.01 (2.27)	0.00
Dad married	-102.34 (62.77)	-55.97	0.01 (0.16)	0.00	-0.06 (0.19)	-0.01	-2.50 (2.60)	-1.66
Predicted log wage	-20.02 (148.68)	-11.34	0.28 (0.33)	0.11	0.37 (0.41)	0.11	154.96*** (8.93)	104.73
Black	83.52 (60.42)	48.51	-0.30** (0.09)	-0.09	-0.18 (0.12)	-0.04	-1.20 (2.15)	-0.81
Other	134.29 (107.61)	80.39	0.02 (0.18)	0.01	0.16 (0.18)	0.03	9.29** (2.95)	6.74
Lagged BMI	-1.78 (2.01)	-1.01	0.05*** (0.01)	-0.02	0.04*** (0.01)	-0.01	-0.34** (0.11)	-0.23
No. of sisters	-43.17*** (9.73)	-24.45	0.02 (0.02)	0.01	0.00 (0.03)	0.00	0.21 (0.42)	0.14
Spouse's ADL needs	-39.02* (15.29)	-22.10	0.03 (0.06)	0.01	-0.10 (0.08)	-0.03	0.33 (1.30)	0.22
No. coresident children	-14.62 (17.38)	-8.27	-0.01 (0.05)	0.00	-0.10 (0.07)	-0.03	0.00 (1.04)	0.00
No. of Spouse's sisters	-25.16** (9.24)	-14.25	0.02 (0.03)	0.01	0.01 (0.03)	0.00	-0.04 (0.58)	-0.03
Rho: Care			0.03 (0.04)		0.03 (0.04)		-0.15** (0.06)	
Sigma: Person Effect	497.85*** (77.04)		0.95*** (0.06)		1.14*** (0.07)		24.17*** (0.69)	
Sigma: Pure Noise	537.11*** (60.01)		1.00		1.00		15.82*** (0.64)	

**Significance:** \*' = 5%; '\*\*' = 1%; '\*\*\*' = 0.1%. **Standard errors are Huber-corrected.**

**Controls:** in-law needs and marital status, age, education, smoking status, number of brothers, marital status, spouse's age, spouse's work experience, spouse's brothers, wealth and wave dummies.

Table 1-3 : Determinants of Time Allocation: Men

	Care	Care (dy/dx)	Mod.	Mod. (dy/dx)	Vig.	Vig. (dy/dx)	Work	Work (dy/dx)
Constant	-116.62 (526.77)		-0.24 (1.63)		-0.29 (1.88)		-30.38 (34.49)	
Mom not left alone	120.53* (57.62)	64.53	0.04 (0.13)	0.01	-0.19 (0.15)	-0.04	-4.98* (2.06)	-3.88
Mom has ADL needs	100.91** (37.05)	53.06	0.16 (0.11)	0.04	0.06 (0.13)	0.01	1.41 (1.65)	1.14
Dad not left alone	200.25*** (59.55)	114.29	0.15 (0.19)	0.04	-0.17 (0.23)	-0.04	4.04 (2.73)	3.30
Dad has ADL needs	186.95** (63.20)	105.34	-0.18 (0.16)	-0.05	-0.33 (0.19)	-0.07	-1.44 (2.29)	-1.14
Mom died with illness	275.31*** (52.48)	163.18	0.10 (0.12)	0.03	0.00 (0.14)	0.00	2.04 (1.83)	1.65
Mom died w/o illness	182.60*** (43.95)	102.91	-0.14 (0.18)	-0.04	0.31 (0.21)	0.07	6.02* (2.66)	4.97
Dad died with illness	160.37*** (48.06)	88.70	0.12 (0.15)	0.03	0.07 (0.17)	0.02	-4.23 (2.39)	-3.31
Dad died w/o illness	46.60 (41.64)	23.68	0.49* (0.21)	0.13	-0.15 (0.25)	-0.03	3.08 (3.04)	2.51
Mom married	-49.45 (73.23)	-23.39	0.15 (0.14)	0.04	0.02 (0.17)	0.00	-1.30 (2.54)	-1.03
Dad married	93.18 (61.83)	48.22	-0.23 (0.17)	-0.07	0.03 (0.20)	0.01	-2.16 (2.68)	-1.72
Predicted log wage	-141.90 (199.13)	-69.36	0.41 (0.58)	0.16	0.57 (0.67)	0.21	77.53*** (12.18)	62.12
Black	130.87*** (39.14)	69.53	-0.15 (0.11)	-0.04	-0.01 (0.13)	0.00	-9.59*** (2.23)	-7.34
Other	133.51 (80.37)	72.24	-0.10 (0.15)	-0.03	-0.12 (0.20)	-0.03	5.72 (3.23)	4.71
Lagged BMI	3.42 (1.88)	1.67	0.03*** (0.01)	-0.01	0.04*** (0.01)	-0.02	-0.13 (0.13)	-0.10
No. of sisters	-17.39** (5.68)	-8.50	0.01 (0.02)	0.00	0.02 (0.03)	0.01	-0.26 (0.41)	-0.21
Spouse's ADL needs	-21.96 (12.91)	-10.73	0.00 (0.05)	0.00	-0.07 (0.06)	-0.02	-1.65 (0.95)	-1.32
No. coresident children	-24.07** (9.07)	-11.76	0.01 (0.04)	0.00	-0.06 (0.05)	-0.02	0.52 (0.71)	0.41
No. of Spouse's sisters	-4.71 (5.41)	-2.30	0.01 (0.02)	0.00	0.04 (0.03)	0.01	0.30 (0.38)	0.24
Rho: Care			0.16** (0.05)		0.08* (0.04)		-0.08* (0.04)	
Sigma: Person Effect	294.95*** (38.35)		0.97*** (0.05)		1.28*** (0.07)		25.32*** (0.67)	
Sigma: Pure Noise	358.30*** (32.07)		1.00		1.00		17.11*** (0.45)	

**Significance:** '\*'= 5%; '\*\*'=1%; '\*\*\*'=0.1%. **Standard errors are Huber-corrected.**

**Controls:** in-law needs and marital status, age, education, smoking status, number of brothers, marital status, spouse's age, spouse's work experience, spouse's brothers, wealth and wave dummies.

## **Essay 2: How Does Dementia Onset in Parents Influence Adult Children's Wealth?**

### **2.1 Introduction**

The American population is aging at an accelerated pace. By 2050, the number of individuals age 65 and older is projected to more than double and to comprise about 20% of the entire population, up from 12% in 2000 and 8% in 1950 (Congressional Budget Office, 2013). As a consequence, the prevalence of age-associated chronic diseases is also expected to surge. Dementia is a disease of particular concern because it is a debilitating condition that affects memory and cognition and eventually leads to a loss in independent functioning, thus necessitating the demand for extensive long-term care (LTC).

Families, especially adult children, are seen as a first line of defense in providing care and support to the elderly with a chronic illness or disability (Carmichael et al., 2008; Van Houtven and Norton, 2004). There are a variety of channels through which adult children respond to parents' LTC needs. Soldo and Hill (1993) note that upstream intergenerational transfers entail three "currencies" or forms: time, money and residential space. With the projected doubling of the elderly in the U.S., there are growing concerns relating to the economic cost of parents' LTC needs on their adult children. Citing the wide ranging impact of dementia, President Obama signed the National Alzheimer's Project Act in 2011, an important goal of which is to improve the ability of the federal government to track the monetary costs of dementia incurred by individuals *and* their families (National Alzheimer's Association, 2012).

In this paper, I use seven waves of longitudinal data (1998-2010) from the Health and Retirement Study (HRS) to investigate the impact of reported dementia onset among elderly parents on the subsequent change in their adult children's wealth. The data includes information

on children before and during parental illness. In order to increase the relevancy and applicability of this research, and to facilitate a clearer interpretation of findings, I focus only on unmarried adult children. To check for robustness of results, I examine the effect for unmarried only children. Further, I also analyze the possibility of delayed effects and the various mechanisms for wealth changes.

This paper makes three contributions. First, it extends the limited existing literature on financial consequences of parents' LTC needs. Even though family care to older adult has been a key topic of research for many years, the emphasis of this work has mainly been on health and social consequences of care provision (Keating et. al., 2013).

Second, by examining a broader financial outcome, household wealth, this paper allows for a relatively more comprehensive attribution of parents' LTC-related monetary costs. Currently, the few studies on financial implications of parents' chronic needs largely examine the opportunity costs of informal care in terms of lost wages and reduced hours of work (Keating et al., 2013). This literature is yet to reach a consensus. Lilly et al. (2007) and Van Houtven, Coe and Skira (2013) provide recent reviews of work in this area. More importantly, as noted above, labor market effects only relate to the time tradeoff associated with informal caregiving, thus overlooking other transfer "currencies" as well as the potentially simultaneous nature of all three forms of transfers.

Third, it overcomes the tendency of existing literature to focus only on caregiver-related outcomes. To my knowledge, all existing studies that specifically analyze financial impact for family members of the elderly (Hurd et. al., 2013; Greenfield, 2013; Wakabayashi and Donato, 2009) examine these consequences for those who provide informal care to the elderly. However, informal caregiving is not a prerequisite for incurring monetary costs on account of parents' ill

health – i.e., adult children who do not provide informal care may still bear a financial burden if they provide monetary assistance or incur out-of-pocket expenditures on behalf of parents. This paper addresses this limitation by examining the effect of parents' dementia on the wealth accumulation of their adult children in general, irrespective of the adult child's status as an informal caregiver.

The paper is organized as follows: Section 2.2 provides background on various channels through which dementia onset among parents may influence an adult child's wealth. Section 2.3 lays out the methodology. Section 2.4 describes the data. Section 2.5 discusses the empirical strategy and findings, and Section 2.6 concludes.

## **2.2 Background**

Previous literature generally suggests that the provision and support of LTC to elderly parents is likely to lead to negative financial consequences for the adult child. According to Fast et al. (1999) and Keating et al. (2013), there are two main channels through which this might occur. First, families can incur out-of-pocket expenses in response to health needs of a parent. These expenses may include payments for formal care (nursing home stays, assisted living facilities, home-based personal care), medical supplies, doctor visits, transportation, household items and utilities. Adult children may also incur expenditures for purchasing professional services (physical therapists, geriatricians, lawyers) on behalf of the parent. They may also spend on home modifications such as ramps and bathroom grab bars. Because dementia undermines parents' ability to function independently, it can also motivate decisions regarding co-residence or proximity, which in turn may entail moving or other transaction costs. Adult children may also incur personal expenditures such as payments for respite care, housekeeping and child care



(for those individuals in the “sandwich generation”), as well as alternative health services (like counseling, massage, yoga, and so on).

Second, adult children may face direct losses in labor income if they take time off from work, leave full-time jobs for more flexible part-time jobs, forgo promotions or quit work altogether. While working on a part-time or an hourly basis may offer a flexible schedule, it can also lead to wage penalties. Wage penalties, temporary time off or early retirement may all lead to lower contributions to Social Security, while the take-up of part-time jobs can specifically cause a loss of access to employer-sponsored retirement and health insurance plans. Out-of-pocket expenditures combined with foregone income due to negative employment consequences could potentially cause the adult child to dip into savings or to borrow in order to smooth consumption over the entire period of the parent’s LTC needs.

Scholars also note that a dementia diagnosis in particular can exacerbate these negative consequences. For instance, formal care for dementia is relatively more expensive than formal care in general: while it costs about \$3,300 per month for a typical one-bedroom apartment in an assisted living facility, the average cost for the same in a “memory care unit” – a special wing in an assisted living facility that provides 24 hours supervised care for dementia patients – is about \$6,000 for a single resident (Adler, 2013). Further, Carpenter and Dave (2004) suggest that following a dementia diagnosis, friendship (including neighbors) networks may shift if peers distance themselves because they do not understand the disease or attach a stigma to it. The authors also note that certain states mandate reporting a dementia diagnosis to the Department of Motor Vehicles causing some patients to lose driving privileges due to their newly learnt status. Diminishing alternative support networks and parent’s inability to drive may intensify care responsibilities on the adult child.

From a theoretical standpoint, parental illness need not necessarily lead to a reduction in an adult child's wealth if the elderly transfer assets in order to "spend down" for Medicaid eligibility. Medicaid is one of the most important sources of LTC (including institutional care) financing in the U.S. but because it is a means-tested program, it covers LTC only for those who are poor or have become poor in the process of paying for their long-term or medical care. Thus, for many elderly, Medicaid is an insurance program with a deductible equal to one's non-housing wealth, creating strong incentives to transfer that wealth to their children. Such a transfer basically allows the elderly to protect their bequeathable wealth. Studies have found that there is little enforcement of restrictions on the transfer of assets, and that there exists a network of professionals to help the elderly successfully shield their assets from Medicaid (Moses, 1990; Sloan and Shayne, 1993). Given these various mechanisms, the financial burden of parents' long-term care needs remains an empirical question.

### **2.3 Modeling the Effect of Parents' Health on Adult Child's Wealth**

In estimating the effect of own-health on own-household wealth, previous literature has had to confront the endogenous relationship between health and wealth, due to the likely reciprocal causal linkage between health and wealth (i.e., reverse causality) and the possibility that unobserved factors make some people both healthier and wealthier (i.e., omitted variable bias).

These issues persist in an intergenerational analysis as well. Previously, I discussed different channels through which parents' health can influence an adult child's wealth. At the same time, it is also possible that an adult child's wealth influences their parents' health.<sup>7</sup> In

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<sup>7</sup> For instance, wealthier adult children can facilitate parents' access to timely and high-quality health care. On the other hand, given their high opportunity cost of time, wealthier individuals may be less likely to provide informal care to parents, thus potentially influencing the parents' health in a negative way.

addition, due to intergenerational persistence in health (Johnston et al., 2013), there may exist unobserved genetic or family background factors that can influence both parents' health as well as the adult child's wealth.

To address the endogeneity problems in the own-health and own-wealth case, Smith (1999) used panel data to estimate the impact of onset of critical health conditions such as cancer or lung disease on changes in wealth, conditioning on initial health status. The key assumption here is that a new diagnosis can be treated as plausibly exogenous because it is unlikely to be caused by a year-to-year change in wealth. Further, because initial health status is correlated with unobserved heterogeneity, controlling for it helps to control for unobservable factors. In other words, controlling for baseline health increases one's confidence that the remaining statistical variation in new onsets is "news" (Smith, 1999).

This method has been widely applied by other scholars as well. Extending the above strategy to couples, Wu (2003) demonstrated that new disease onsets among wives have a larger impact on household wealth than those among husbands. Lee and Kim (2008) examined the effect of health shocks on the wealth of elderly, finding that new health events lowered wealth in elders during the period in which they occurred. The authors, however, did not include dementia onset as a potential health shock.

To identify the effect of parents' LTC needs on adult child's wealth, I follow a similar approach using longitudinal data on adult child's household savings decisions in combination with a plausibly exogenous measure of change in parental health: the onset of dementia. To my knowledge, this is the first paper that estimates the effect of new health events on wealth changes in an intergenerational framework. The general regression equation for this analysis is specified as follows:

$$\Delta wealth_t = \beta_0 + \beta_1 DementiaOnset_t + \beta_2 BaselineHealth_{t-1} + \beta_3 X + \mu_t \quad (1)$$

Here,  $\beta_1$  is the coefficient of interest which represents the differential change in wealth in the case of parental dementia onset, relative to no parental dementia onset. Baseline health represents the health of the parent before any dementia diagnosis was reported.  $X$  represents other control variables and  $\beta_3$  is a vector of coefficients on these controls.

I focus the analysis only on unmarried adult children for three reasons. First, past research has found marital status to be an important determinant of an adult child's caregiving behavior. Unmarried individuals are more likely to provide informal care (Dwyer and Cowrad 1991; Wolf, 2014) and financial support (Lee and Aytac, 1998) to parents compared to married couples. Having an unmarried child also increases the probability of co-residence (Pezzin and Schone, 1999). It is possible that families employ a selection process where the elderly tends to rely on the child with fewest competing responsibilities for their care needs (Brody, 2006). However, other scholars have demonstrated that these differences between married and unmarried in the provision of informal care and financial support to parents persist even when structural characteristics like time demands, needs and resources, and demographic and extended family characteristics are controlled (Sarkisian and Gerstel, 2008). This suggests that in analyzing the effect of parents' LTC needs, unmarried individuals form a more relevant study population.

Second, marriage inevitably adds complexity to family structure leading to difficult specification issues. Married couples may share the burden of informal care among each other. They can also self-insure, i.e., if increasing care responsibilities lead to reduced earnings or early exit from the labor force for an adult child, then the spouse may compensate by increasing work effort (either in hours or years of work) (Coe, Skira and Van Houtven, 2011). Additionally,

married couples likely have two sets of parents. On the one hand, this may represent competing claims on a households' time and resources. On the other, they may receive an inheritance from one set of parents (due to death of a parent or in-law) and dissave (due to health needs of a parent/in-law) on account of the other set. Further, a couples' wealth response is also conditioned by the presence of two sets of sibling networks that can provide alternative sources of time and resources. Thus, controlling for all possible patterns of response would require the inclusion of several variables and their interactions. However, given the modest incidence of dementia, modeling these complexities is expected to use up too many degrees of freedom.

Third, if couples make decisions about "big-ticket" items like parents' nursing home or assisted living expenses as a collective, they may face intra-household bargaining pressures. In this case, the allocation of resources in response to a parental dementia diagnosis may depend of which spouse has more bargaining power (Lundberg and Pollack, 1996). Using household level data from Indonesia, Khemani (1999) does find evidence of bargaining between husbands and wives over transfers to their respective parents. Therefore, depending upon the division of labor in a given household, there may be differences in the strength of household response on the basis of whether dementia occurs for the husbands' parents or the wife's parents. In contrast, unmarried individuals are likely to enjoy substantial control over decisions relating to supporting parent's LTC needs.

## **2.4 Data**

The data for this analysis come from the Health and Retirement Study (HRS), a nationally representative, longitudinal survey of individuals age 51 and older. The HRS began in 1992 and individuals are interviewed every even numbered year. The age profile of the respondents makes their parents prime candidates for needing LTC. The HRS provides in-depth

information about the economic status of households (including wealth and income) and parents' LTC needs.

#### 2.4.1 Sample and Measures

The sample I create from the HRS spans 1998-2010 (questions on parent's memory disease were asked for the first time in 1998). It includes unmarried adult children (separated, divorced, widowed, or never married) observed over three consecutive waves: "baseline" wave (w-2), "lagged" wave (w-1) and "current" wave (w). Because the HRS is a biennial survey, the time period from baseline wave (w-2) to current wave (w-1) is a four-year window. An individual can have a maximum of five person-wave observations: the earliest can occur when "current" wave equals 3 (2002) and the latest can occur when "current" wave equals 7 (2010).

With regard to parents' health, the HRS asks the respondent whether a "*doctor ever said that your parent has a memory-related disease?*" As illustrated in Figure 2-1, the sample is restricted to those who report at least one living parent in the baseline wave (w-2) and lagged wave (w-1), and that none of the living parents ever received a dementia diagnosis in the baseline wave (w-2). The main independent variable – *dementia onset in parents* – is a dummy that equals 1 if at least one parent received a dementia diagnosis in the lagged wave (w-1). I call this the "treatment group." *Dementia onset in parents* equals 0 if none of the parents received a dementia diagnosis in the lagged wave (w-1). This is the "control group."

The dependent variable is the difference in total household wealth between the current wave (w) and the lagged wave (w-1). Household wealth equals the total value of all assets, minus total debts. Household assets consist of financial and nonfinancial assets, including housing equity, other real estate, vehicles, business equity, IRA or Keogh or retirement accounts, stocks or mutual funds, checking, savings or money-market funds, CDs, government bonds or treasury

bills, other bonds, and other assets. Total debts are the sum of all reported debts. All dollar figures are expressed in 2010 dollars.

While change in wealth is measured between current wave (w) and lagged wave (w-1), change in parental health is measured between lagged wave (w-1) and baseline wave (w-2). This is because I assume that any change in wealth as a result of parent receiving a memory disease diagnosis is unlikely to be contemporaneous. The adult child may adjust out-of-pocket expenditures to assist the parent in the short-term.

In order to avoid issues relating to receipt of inheritance, I exclude those adult children who report that the diagnosed parent died by current wave (w). Analogously, in the control group, I restrict the analysis to those who continue to have at least one living parent in current wave (w). This results in the loss of 389 cases. After deleting cases with incomplete information, there 1,540 person-wave observations (699 unique observations) for unmarried individuals.

As described in the previous section, it is important to control for baseline health conditions of the parent that make some parents more susceptible to memory disease than others. Unfortunately, the HRS does not include information on the parent's own or family medical history. I attempt to overcome this by controlling for whether the adult child provided substantial support to parents in completing Instrumental Activities of Daily Living (IADL) in the baseline year. IADLs are essential for an individual to live independently in the community and include activities such as household chores, managing finances and medication, transportation, and so on. Previous research has indicated that IADL disability is a useful predictor for diagnosing dementia at 1- and 2-year follow-up (Sikkas, 2011).

For IADL help, the HRS asks respondents: *“Did you spend a total of 100 or more hours [since last interview] helping your (deceased) [parents/in-laws] with things such as household*

*chores, errands, transportation, etc.?*” If the answer to this question is “yes” then the respondent is asked: “*Roughly how many hours did you spend [since last interview, in the last two years] giving such assistance to your parents/in-laws?*”

A sizeable proportion of individuals who responded affirmatively to providing more than 100 hours of IADL help answered “don’t know” to the subsequent question on the actual number of help hours. These respondents were then asked a follow-up question asking them to choose from among three possible ranges of help hours: 0-199 hours; 200-499 hours; and 500-5000 hours. Responses in the middle or the top category are assumed to represent the provision of “substantial” IADL help to parents. In addition to IADL help, I also control for parents’ age. Parent’s age is measured as the maximum age across living parents in the baseline wave (w-2).

Other correlates include wave dummies, respondent’s age, race and education, as well as, parent’s education measured as the maximum education among parents in the baseline wave (w-2).

#### **2.4.2 Summary Statistics**

Table 2-1 presents descriptive statistics for the entire sample, and for the treatment and control groups separately. The average age of the sample is 63. A large majority of the sample - over 70% - is women. This is because women are less likely to remarry after a divorce (Livingston, 2014) and also tend to outlive men, and are therefore more likely to be un-partnered.

The percentage of treated cases in the sample is about 7%. This is lower than population estimates - according to Plassman et al. (2007), the prevalence of dementia among individuals age 71 and older is about 14%. One reason for this is because I restrict the analysis to only those cases where the parent receiving dementia diagnosis survives until current wave (w). Without conditioning on the ill parent being alive in the current wave (w), the percent of treated cases is about 11%, which is in the range of population estimates. It is also important to keep in mind that Memory disease is also a commonly late- and under-diagnosed condition. While family members



may notice changes in daily functioning of the elderly, it often does not directly lead to a consultation with a healthcare professional. This is because family members misattribute these symptoms to those of normal aging or stress (van Vliet et al., 2011). Evidence of untimely dementia diagnosis suggests that the treatment variable in the regressions may be measured with error. Controlling for initial health status of the parent, it is unlikely that the timing and accuracy of dementia diagnosis differs systematically among adult children. Thus, the measurement error in dementia diagnosis is likely to bias the coefficients towards zero and provide a conservative estimate of the true result.

The provision of substantial IADL support in the baseline wave is higher in the treatment group than in the control group. The difference is statistically significant at 1%. This is expected and appears to support the findings from previous literature. In addition, parents in the treated group are slightly older than parents in the control group. This is also expected as the prevalence of dementia increases with age. There are no statistically significant differences in respondent's race and education between the treatment and control groups.

The mean change in wealth between current wave ( $w$ ) and lagged wave ( $w-1$ ) for the entire sample is about  $-\$23,000$ . However, the standard deviation for the measure is quite large, suggesting that the mean may not represent an adequate summary of the variable. Therefore, I also provide values for the 25<sup>th</sup>, 50<sup>th</sup> and 75<sup>th</sup> quantiles of the wealth change distribution. For the full sample, there is no change in wealth at the median. Values at quantiles above the median reflect wealth accumulation while those below the median reflect wealth de-accumulation.

A simple estimation (with no other covariates and bootstrapped standard errors) shows that there is no statistically significant difference in wealth accumulation for those in the treatment group relative to those in the control group at the 25<sup>th</sup> quantile and at the median.

However, at the 75<sup>th</sup> quantile, being in the treatment group is associated with a reduced level of wealth accumulation and this difference between the two groups is statistically significant.

## **2.5 Results**

### **2.5.1 Main Results**

To identify the effect of parental dementia onset, I regress the change in unmarried adult child's wealth between current wave ( $w$ ) and lagged wave ( $w-1$ ) on the treatment variable for lagged dementia onset in parents (see equation 1). I control for the unmarried adult child's age, race, and education, parent's age, parent's education and a dichotomous variable for whether the child provided any parent with substantial amount of IADL support in the baseline wave ( $w-2$ ). The empirical model also controls for wave dummies.

Although the asset data from the HRS is of very high quality, scholars have noted the presence of noise in wave-to-wave change in wealth (Hill, 2006). In addition, because wealth data contains many outliers, Ordinary Least Squares (OLS) is expected to yield imprecise estimates (Wu, 2003). Researchers often apply natural log transformations to adjust for skewness in wealth. However, natural log may not be the most appropriate transformation for measures of net wealth and change in wealth as both include zero and negative values.

Further, an OLS regression estimates the average effect, but it possible that parental dementia onset influences points other than the mean of the response distribution. For instance, individuals who incur large amount of debt between waves may be less able to deplete wealth on account of parents' illness. Correspondingly, those who are able to save between waves – in other words, those who have wealth to deplete – may be more able to spend on parents' LTC needs.

To address the issue of skewness and to investigate the effect of dementia onset in parents along different locations of the wealth change distribution (called the savings distribution from hereon), I estimate the model using the unconditional quantile regressions (UQR) estimator proposed by Firpo, Fortin, and Lemieux (2009). In contrast to the conventional quantile regression framework, the unconditional quantile regression method provides more interpretable results as it marginalizes the effect over the distributions of other covariates in the model.

Table 2-2 presents estimates of  $\beta_1$  from the specification described in equation 1 in which parameters are estimates of various quantiles of the savings distribution. A limitation of UQR is, at the time of writing, that there is no statistically valid method to cluster standard errors. I rely on bootstrapped standard errors using 500 repetitions in my UQR regressions.

There is little effect of dementia onset on the unmarried adult child's savings at all lower quantiles of the distribution. That is, among those who dissave or do not add to their wealth between-waves, there is no statistically significant effect of receiving a parental dementia diagnosis on wealth. However, above the median, the differential effect of being in the treatment group relative to the control group is negative and statistically significant. Specifically, as indicated in Table 2-2, a parental dementia diagnosis decreases an unmarried adult child's household wealth accumulation by about \$7,300 at the 55<sup>th</sup> percentile. When compared to the unconditional 55<sup>th</sup> percentile of wealth change for the entire sample - \$1,266- this represents a very large decrease. In fact, at the 55<sup>th</sup>, 60<sup>th</sup>, 65<sup>th</sup>, and 75<sup>th</sup> quantiles, belonging to the treatment group potentially wipes out any savings whatsoever.

At the 90<sup>th</sup> quantile, as a result of parents' dementia diagnosis, the treatment group is saving about \$57,000 less than the control group. As compared to the 55<sup>th</sup> quantile, this reduction is relatively smaller (~41%) given that the 90<sup>th</sup> quantile of the response variable is \$137,411.

Thus, towards the very top of the savings distribution, the effective magnitude of the treatment effect (or the relative “pinch” due to parents’ dementia diagnosis) becomes a little smaller.

### 2.5.2 Robustness Check

The main empirical result of this paper indicates that a parental dementia diagnosis leads to reductions in wealth for unmarried individuals in the upper quantiles of the savings distribution. Intuitively, this reduction in wealth accumulation should be steeper for those unmarried children who are also only children, i.e., those without siblings because they have to potentially bear the entire parent care burden independently.

To account for siblings, I create a dichotomous variable, *presence of siblings*, which equals 1 if the adult child has one or more siblings and 0 otherwise. 8.4% of the sample has no siblings. To examine how parent’s dementia diagnosis influences the wealth of unmarried only children, I interact the variable, *presence of siblings*, with the treatment variable. With the inclusion of the main effect and the interaction, the coefficient on the treatment variable estimates the effect for an unmarried adult child with no siblings.

As hypothesized, coefficient estimates illustrated in Figure 2-2 demonstrate that the negative effect of parents’ dementia diagnosis are larger for unmarried only children. For instance, among unmarried only children, at the 55<sup>th</sup> and 75<sup>th</sup> percentiles, a dementia diagnosis in parents leads to a reduction in wealth of about \$29,000 and \$68,000 respectively. In the case of unmarried only children, the treatment effect is also statistically significant for a larger part of the distribution. In addition to most upper quantiles of the savings distribution, the parents’ dementia diagnosis also leads to a statistically significant negative effects at the 45<sup>th</sup> and 50<sup>th</sup> quantiles. The coefficients for quantiles lower than the 45<sup>th</sup> quantile remain insignificant.

### 2.5.3 Delayed Effects

To examine if negative effects of parental dementia diagnosis persist over time, I extend the analysis over four waves instead of three. In addition to the baseline wave (w-2), lagged wave (w-1) and current wave (w), I also include a “next wave (w+1).” I condition this analysis on the dementia diagnosed parent remaining alive until next wave (w+1) in the treatment group, and at least one parent remaining alive in the next wave (w+1) for the control group. This reduces the sample size to 887 cases.

Change in wealth is analyzed over next wave (w+1) and current wave (w), while dementia onset in parent is still measured over lagged wave (w-1) and baseline wave (w-2). To illustrate, for an unmarried adult child who entered the sample for the first time in 1998, dementia onset is captured between 2000 and 1998, while change in wealth is now measured between 2004 and 2002. This represents a six-year window.

Table 2-3 shows the quantile regression coefficients for this analysis. The pattern of findings is similar to the main results, i.e., a parental dementia onset influences household savings at upper quantiles of the savings distribution. These findings indicate that in the upper quantiles of the savings distribution, unmarried individuals who received a parental dementia diagnosis as far back as five years ago are still saving less or dissaving as compared to those whose parents did not receive a dementia diagnosis.

### 2.5.4 Mechanisms

As discussed in Section 2, parents' LTC needs can negatively influence an adult child's wealth through two channels: out-of-pocket expenses, providing monetary assistance, and losses in labor income. In this section, I will attempt to examine the potential roles of both mechanisms in leading to a reduction in an unmarried adult children's wealth.

Previous research has indicated that formal care expenses (particularly for nursing homes) comprise a substantial part of the overall out-of-pocket expenditures borne by caregivers (Evercare and NAC, 2007). In order for this to occur, a dementia diagnosis should increase the likelihood of parent residing in a nursing home. To provide empirical evidence on this, I estimate a probit regression where the dependent variable is 1 if an unmarried adult child's parent resides in a nursing home at current wave (w) and 0 otherwise. The key independent variable of interest is dementia onset between waves (w-1) and wave (w-2). In addition to the controls used previously, I also control for whether parent was in a nursing home in wave (w-1). Robust standard errors are clustered by household ID.

Marginal effects reported in Table 2-4 indicate that net of covariates, a dementia diagnosis does indeed lead to a 6 percentage point increase in the probability of a parent residing in a nursing home at current wave (w). This provides suggestive evidence that expenditure on nursing homes may be a likely mechanism through which the depletion in adult child's wealth occurs.

Next, I examine whether parents' dementia diagnosis leads to changes in an unmarried adult child's household income. The setup is similar to the wealth case described in the main section, except here, the key dependent variable is change in adult child's household income (between current wave (w) and lagged wave (w-1)). All dollar figures are expressed in 2010 dollars. To make the analysis relevant to those in the labor force, I restrict it to individuals below age 65. This reduces the sample size to 991 cases. I estimate the model using unconditional quantile regressions.

Similar to the pattern in the wealth regressions, I find (Figure 2-3) that for a large section of the upper income change distribution (60<sup>th</sup>, 65<sup>th</sup>, 75<sup>th</sup>, 80<sup>th</sup>, and 85<sup>th</sup> quantiles), having a parent with dementia onset leads to a reduction in household income. There are no statistically

significant effects at lower quantiles of the income change distribution. In other words, for those unmarried children who add to their household income between-waves, being in the treatment group, relative to the control group, leads to reductions in household income. Further, these effects only show up when I restrict the sample to those below age 65 – when the entire sample is considered, being in the treatment group leads to small and statistically insignificant effects for almost the entire distribution of the dependent variable (results available on request). This finding lends support to the idea that reductions in wealth may also come from reductions in household income following a parents' dementia diagnosis.

## **2.6 Conclusion**

Americans are living longer, but with increased longevity comes a growing need for long-term care services and supports. Unmarried adult children shoulder a disproportionate amount of responsibility in ensuring that the elderly parent receives such care. Because adult children at this stage are also likely to be planning and saving for their own retirement, understanding the financial implications of parents' LTC becomes important.

Scholars have previously examined the economic costs borne by family members mainly by studying the employment consequences of providing informal care. I contribute a new strand to this literature by emphasizing broader dimensions of financial outcomes and by also including non-caregiving adult children in the analysis. Specifically, I analyze the effect of dementia onset in parents on the change in wealth of their unmarried adult children.

The findings indicate that parental dementia substantially reduces household wealth of an unmarried adult child in the upper quantiles of the wealth-change distribution in the first two years after a diagnosis is reported. These effects are large and statistically significant - for several upper quantiles, the treatment effect is large enough to wipe out any between-wave savings

observed at that quantile. These effects are more pronounced for unmarried adult children without siblings. Further, this response is observed to persist in the subsequent time period as well. An examination of mechanisms suggests that both, losses in labor income and nursing home expenditures, may play a role in leading to wealth declines for those in the treatment group.

It is important to acknowledge that the policy implications of these findings may not be straightforward. Wealth declines as a result of parental dementia diagnosis are uneven – they appear to be concentrated only among those unmarried adult children who augment their wealth between-waves. In order to better understand the characteristics of these unmarried adult children, using a probit model, I regress an indicator for belonging to the upper quantiles of the savings distribution (above the median) on basic demographic characteristics (age, race and education). For brevity, these results are not included, but available on request. I find that unmarried adult children in the upper quantiles are likely to have higher levels of education, suggesting that those facing wealth depletion consequences as a result of parent's dementia diagnosis may also be more economically advantaged. Thus, even with a potentially targeted policy design, ideals of vertical equity may still be compromised.

More importantly, the nature of public policy intervention depends upon whether this wealth depletion is anticipated or unanticipated in nature. There is evidence that a dementia diagnosis may constitute “new information” to family members: Pratt & Wilkinson (2003) and Aminzadeh et al. (2007) find that patients and their caregivers reported feelings of “shock, fear and depression” upon receiving the diagnosis. Others have described the period immediately following a parents' dementia diagnosis as “distinctive” and “transitional” (Keady and Nolan, 2003; Quinn et al. 2008) because it confirmed the irreversibility of the condition. In fact, before a



diagnosis, many care partners did not consider themselves as “caregivers” (de Vugt and Verhey, 2013). However, it is possible that adult children transfer time and/or money to elderly parents in response to prior parent-to-child transfers (Henretta et al., 1997) or in expectation of receiving an inheritance later (Bernheim, Shleifer and Summers, 1985). If by depleting wealth on account of parents’ LTC needs, individuals are basically carrying out a previously planned wealth path, then a policy that provides financial support to these individuals may not be justified. Future research should consider these questions in greater detail.

That said, even if individuals are able to anticipate some wealth depletion in the future, they may still lack information about the actual costs and duration of parents’ LTC needs. In addition, if individuals discount the future in somewhat inconsistent and inefficient ways, they may underestimate levels of future parental need. Uncertainties relating to the role of other family members in the provision of care and support may also exist. According to Folbre and Wolf (2012), even raising this subject for discussion can be stressful, contributing to tendencies to avoid and procrastinate. Other scholars find that for a large majority of caregivers, the level of planning for the relative’s future care needs and knowledge of formal care services was low (Ducharme et al., 2011). Because this paper finds substantial wealth depletion following a parents’ dementia diagnosis, a case can be made for initiating programs that enhance awareness and financial preparedness for LTC needs among families.

An understanding of the economic impact of LTC on individuals and their families is a prerequisite for an informed policy debate. The findings presented in this paper have important implications for the measurement of “cost” of parents’ LTC needs. They also highlight the importance of considering the distribution of these costs across different individuals.

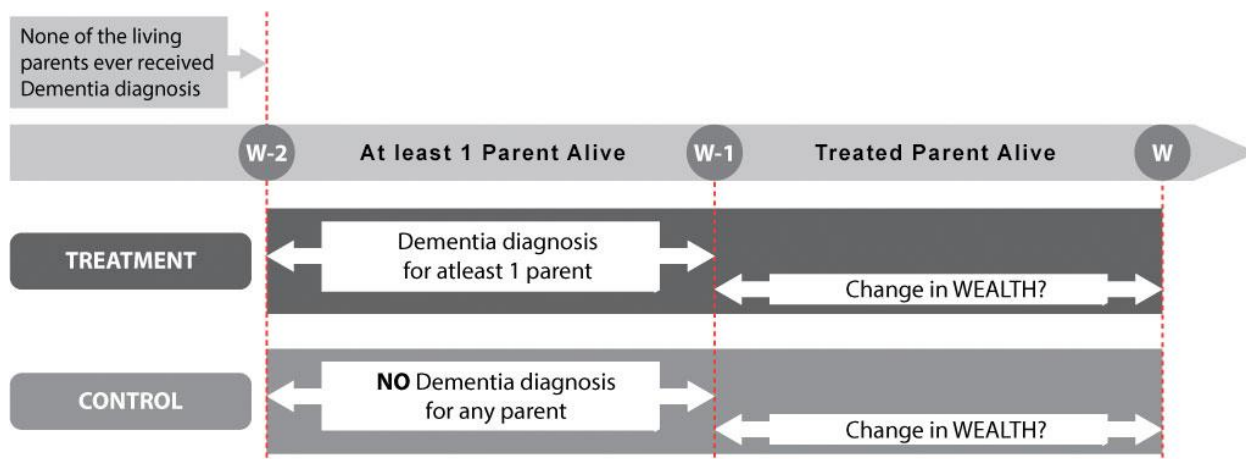
*Figure 2-1 : Sample Selection*

Table 2-1 : Descriptive Statistics

	All	Treatment	Control	T&C Diff.
Treated (%)	7.30			
IADL help - baseline (%)	22	38	21	***
Race: White (%)	69	70.00	69	n.s
Race: Black (%)	26	26	25	n.s
Race: Other race (%)	6	4	6	n.s
High School dropout (%)	18	14	18	n.s
High School graduate (%)	33	37	33	n.s
Some College (%)	23	28	25	n.s
College Plus (%)	23	20	24	n.s
Age	63	64	63	**
	(5.72)	(6.06)	(5.67)	
Female (%)	72	73	72	n.s
Mean Change in Wealth [(w)-(w-1)] (\$)	-23,019	-7,494	-24,248	n.s
	(1,312,029)	(156,244)	(1,362,311)	
25thQ. Change in Wealth [(w)-(w-1)] (\$)	-28,460	-35,025	-28,277	n.s
50thQ. Change in Wealth [(w)-(w-1)] (\$)	0	-2,383	0	n.s
75thQ. Change in Wealth [(w)-(w-1)] (\$)	34,519	13,258	37,354	**
<i>Parent Variables</i>				
Age of oldest living parent	82	85	82	***
	(6.43)	(6.00)	(6.41)	
Max. parent education (years)	10.18	10.16	10.19	n.s
	(3.73)	(3.84)	(3.72)	
<b>Sample Size</b>	1,540	113	1,427	

Notes: \*\*\* Significant at 1%; \*\* Significant at 5%. Standard Deviation in parenthesis

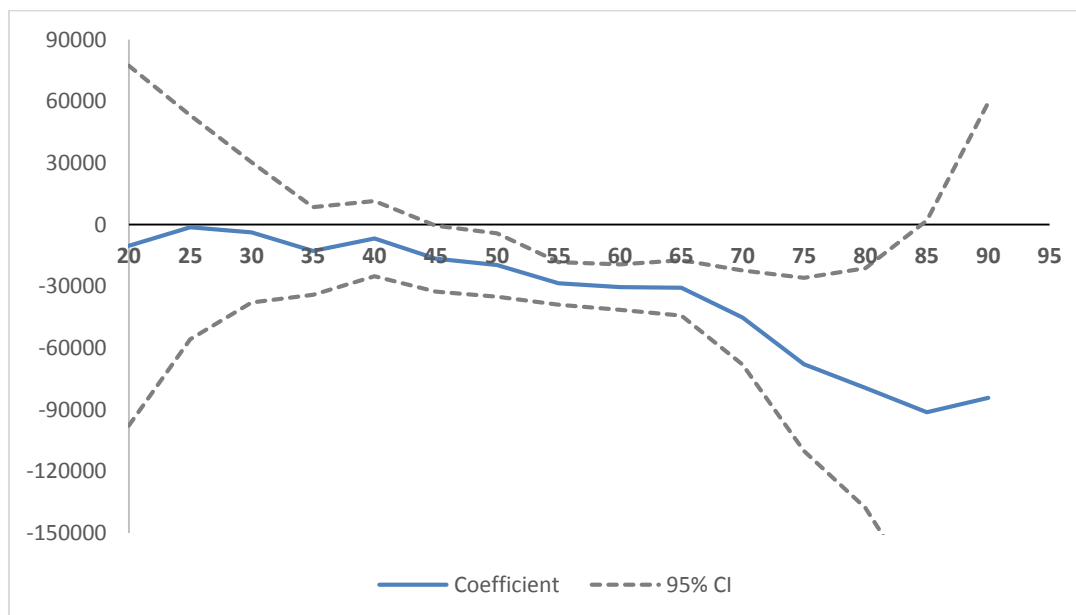
Table 2-2 : *Quantile Regressions of Parent's Dementia Onset and change in Unmarried Adult Child's Wealth*

*Dependent Variable: Wealth (w) - Wealth (w-1)*

	Quantile								
	25th	35th	45th	50th	55th	65th	75th	80th	90th
Sample quantile	-28,460	-8,692	-954	0	1,266	10,350	34,519	55,396	137,411
Dementia onset in parent	-4,867	-5,874	-5,922	-5,082	-7,296	-11,425	-36,693	-34,341	-57,105
<i>t</i>	-0.44	-1.32	-1.59	-1.37	-2.02	-2.62	-3.03	-2.12	-1.91
N	1,540								

All regressions include controls for respondent's age, education, race, parent's education, parent's age at baseline, whether respondent provided care to parent at baseline and wave dummies

Figure 2-2 : Effect of Dementia Onset on Wealth for Unmarried Only Children



*Table 2-3 : Delayed Effect Quantile Regressions of Parent's Dementia Onset and change in Unmarried Adult Child's Wealth*

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*Dependent Variable: Wealth (w+1) - Wealth (w)*

	Quantile								
	<i>25th</i>	<i>35th</i>	<i>45th</i>	<i>50th</i>	<i>55th</i>	<i>65th</i>	<i>75th</i>	<i>80th</i>	<i>90th</i>
Dementia onset in parent	7,138	-3,199	-4,351	-5,552	-11,063	-20,521	-33,690	-54,497	-91,042
<i>t</i>	0.55	-0.48	-0.73	-0.92	-2.02	-3.56	-1.79	-2.52	-2.87
N	887								

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All regressions include controls for respondent's age, education, race, parent's education, parent's age at baseline, whether respondent provided care to parent at baseline and wave dummies

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*Table 2-4: Probit Regressions of Parent's Dementia Onset and Subsequent NH admission*

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*Dependent Variable: Parent in a Nursing Home in Current Wave (w)*

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	<u>Average Marginal Effect</u>	
Between-wave dementia onset in parent	0.06	***
	(0.02)	
Parent in NH in Wave (w-1)	0.25	***
	(0.02)	
Control for Baseline health of Parent?	Yes	
N	1,540	

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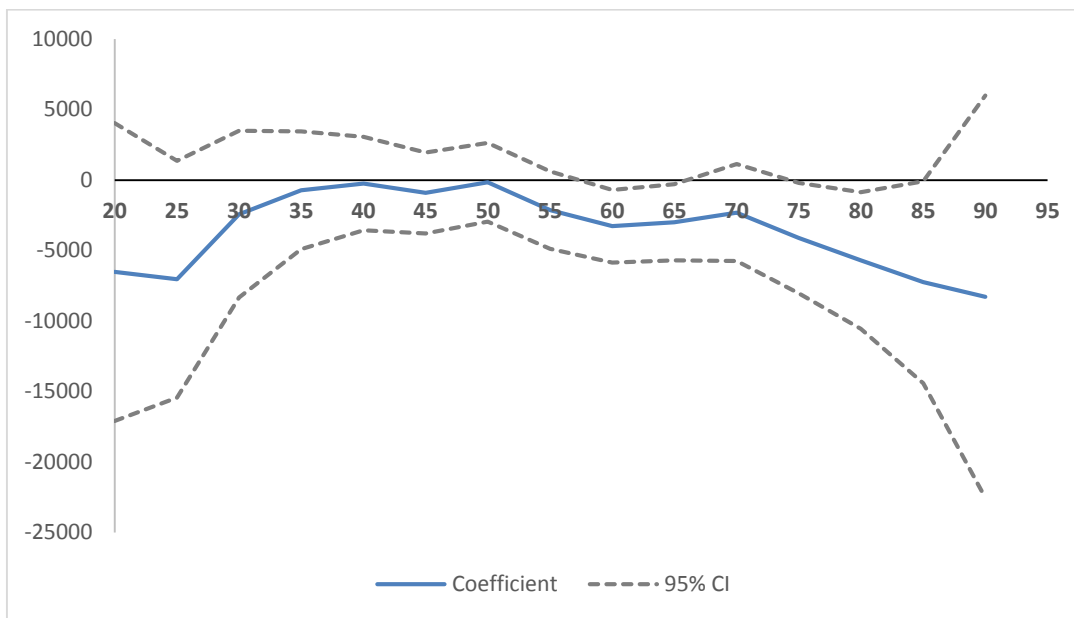
Significance: '\*'=10% '\*\*'= 5%; '\*\*\*'=1%; Standard errors are clustered by household ID.  
 All regressions include controls for respondent's age, education, race, parent's education, parent's age at baseline, whether respondent provided care to parent at baseline and wave dummies.

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Figure 2-3 : Effect of Dementia Onset on Income for Unmarried Children





## **Essay 3: Effect of the Personal Care Services State Plan Option on Medicaid Expenditures**

### **3.1 Introduction**

The health care of elderly Americans is universally insured as an entitlement under Medicare. However, when it comes to helping the very same people with long-term care (LTC), Medicare lends very little protection. A majority of LTC is provided informally by family members and friends. In the public sphere, Medicaid – the joint federal/state health program for low-income Americans – is the nation’s primary safety net for financing LTC. In 2011, a total of \$357 billion was spent on long-term services and supports (LTSS), of which 40%<sup>8</sup> was accounted for by Medicaid (Kaiser Family Foundation, 2013).

When Medicaid was enacted in 1965, coverage for LTC was available almost exclusively for services in skilled nursing facilities, leading to a heavy use of nursing homes (or “institutional bias”). However, this has changed considerably over time due to high costs of facility care, declining quality and consumer preferences to receive LTC in less restrictive settings. In recent decades, developing and expanding home and community-based alternatives has become a priority for most states. This commitment to “rebalance” publically funded LTC away from nursing homes has also been heavily motivated by the 1999 U.S. Supreme Court’s *Olmstead* decision. In its decision, the Court ruled that states must provide services in the most integrated settings appropriate to the needs and wishes of people with disabilities. Further, it also stated that a failure to do could constitute discrimination under the Americans with Disabilities Act (Smith et al., 2000).

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<sup>8</sup> Medicare (which provides limited post-acute care) accounted for 21% of the spending. Direct out-of-pocket expenses accounted for 15% of total LTSS spending, with private insurance and other public and private funding sources covering 7% and 18%, respectively.

In 2009, home and community-based services (HCBS) accounted for 45% of total Medicaid LTC spending (Eiken et al., 2010). While states have considerable flexibility in designing their LTC benefit package under Medicaid, three program features account for the majority of Medicaid HCBS spending: a mandatory home health benefit; a personal care service (PCS) State Plan option and section 1915(c) waivers. While all states are required to provide home health to those who qualify for institutional care, the other two program features are utilized at states' option. A home health benefit provides a nurse or a specialized aide who can assist with tasks such as those that involved in post-surgery rehabilitation at home, including simple dressing changes, monitoring complex diet regimens, taking basic vital signs, patient/caregiver education etc. It may also include medical supplies and equipment suitable for home. A personal care benefit, on the other hand, provides help with daily life tasks such as bathing, grooming, light house-work, and so on. 1915(c) waivers can include a wide range of HCBS services such as case management, home maker services, adult day health, respite, personal care, transportation.

If a state elects to adopt a PCS State Plan option, then similar to the home health benefit, it has to adhere to Federal requirements of "statewideness" and "comparability." That is, personal care services must be available on a comparable basis to all Medicaid eligible beneficiaries who meet a pre-established need criteria. In addition, states cannot restrict the availability of these services to particular geographic regions.

In conjunction with, or in the absence of, the PCS benefit, states may also apply for one or more 1915(c) waivers that allow them to circumvent the "comparability" and "statewideness" requirements of the Medicaid law. With Federal approval, states can use 1915(c) waivers to precisely target a wide range of HCBS services to particular categories of beneficiaries (e.g., the

elderly or the developmentally disabled), as well as limit these initiatives to particular geographic areas. The waivers also permit states to cap the number of participants and establish waiting lists.

The motivation for the development of instruments like 1915(c) waivers stems from the constant dilemma state officials face in promoting access to services on the one hand, and controlling costs on the other. Since 1975, all states have had the option of offering PCS as a Medicaid State Plan benefit (Le Blanc, Tonner, and Harrington, 2001). However, unlike the tremendous growth experienced by 1915(c) waivers<sup>9</sup>, the PCS benefit is yet to be adopted by all states. By 1979, 10 states had adopted the program and this number grew to 25 by the end of 1990 (Litval and Kennedy, 1991). Currently, 32 states (including DC) have adopted the PCS State Plan option. Scholars have argued that the entitlement nature of the program has led to concerns over runaway expenditures, which has hindered nation-wide adoption of the PCS State Plan option (Ruttner and Irvin, 2013; O’Keeffe et al., 2010; American Public Human Services Association/Center for Workers with Disabilities, 2006; Doty, 2000; Weiner and Stevenson, 1998). Surprisingly, despite these concerns, there has been little empirical work that examines whether the PCS State Plan option does in fact lead to an increase in Medicaid expenditures.

This paper fills the void by examining the effect of adopting the PCS State Plan option on Medicaid expenditures over the 1975-2009 period. Because the Medicaid program has evolved substantially over the four decades since the PCS State Plan option was made available to states, I also investigate whether the effect of PCS on aggregate expenditures varies over time. Finally, I provide suggestive evidence on whether states take predicted spending changes into consideration when deciding to adopt the PCS State Plan option.

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<sup>9</sup> Nearly all states and DC offer services through HCBS waivers – currently more than 300 HCBS waiver programs are active nationwide (Medicaid.gov, 2015)

The paper is organized as follows: Section 3.2 provides a background on the Medicaid PCS State Plan option. Section 3.3 reviews literature on the adoption of PCS benefit across states and its relationship to Medicaid expenditures. Section 3.4 lays out the methodology. Section 3.5 describes the data. Section 3.6 discusses the findings, and Section 3.7 concludes.

## **3.2 Background**

Within the range of LTC services is a set of services, generically called “personal care,” that refers to “hands-on” or individualized assistance with activities of daily living (ADLs) such as eating, bathing, dressing, toileting, and may also include instrumental activities of daily living (IADLs) such as grocery shopping, meal preparation, money management, laundry and light housework.

The PCS option was first established administratively in 1975 under the authority of the Secretary of Health and Human Services (Smith, 2000). At that time, it had a medical orientation where services had to be prescribed by a physician, supervised by a registered nurse, and could be delivered only at a person’s residence in accordance with a service plan. Generally, the services included assistance with ADL activities. Personal care workers could help with IADL activities on a limited basis and only if they were incidental to the delivery of ADL assistance (O’Keeffe et al., 2010).

In 1993, Congress formally added “personal care” as an optional category in the Medicaid statute. In doing so, it also broadened the coverage of the PCS benefit. Specifically, it made explicit the non-medical nature of personal care by providing that the PCS benefit did not need to be physician prescribed or nurse supervised. The new regulations also gave states the authorization to provide personal care outside an individual’s home. In subsequent years, Medicaid guidelines allowed payment to relatives, except “legally responsible relatives” (i.e.,

spouses and parents of minor children) for the provision personal care. In addition, they also made supervision or cuing an allowable service (Health Care Financing Administration, 1999). While states were not required to change the scope of their pre-1993 coverage, they could take advantage of the new regulations by amending their existing Medicaid State Plan (O’Keeffe, 2010).

The financial eligibility for the PCS optional benefit is determined using each state’s standard Medicaid eligibility criteria for the categorically needy. These criteria are usually more restrictive than those used to qualify persons for institutional placement or for a 1915 (c) waiver. The PCS option can be used to provide services to individuals who have functional limitations but do not necessarily meet the institutional level of care criteria. Thus, unlike income eligibility, the PCS is less restrictive on need criteria as compared to 1915(c) waivers which require individuals to have needs that qualify them for institutional level of care. That said, according to Le Blanc, Toner and Harrington (2001), states vary quite a bit in terms of the functional need criteria they set for PCS eligibility. Additionally, the authors also note that most states with PCS program impose formal limits on service use (hourly limits and/or cost caps) and engage in low provider reimbursement to restrict the growth of these programs.

### **3.3 Literature Review**

The earliest studies on the PCS State Plan option were done by Litval and Kennedy (1991). These studies were based on two national surveys of PCS programs conducted in 1985 and 1990, as well as site visits to six states which utilized the PCS option. According to the authors, initial adopters of the program saw the PCS benefit as one of the few vehicles for leveraging federal dollars to expand personal assistance services in an era of shrinking state revenues. Prior to that, many states had been using the limited Title XX Social Service Block

Grants and other state funds to cover personal care. However, due to new fiscal constraints and budget deficits (for instance, in Michigan in 1978), states began to examine the possibility of accessing uncapped matching federal funds through Medicaid for this purpose.

Because PCS State Plan is an optional program, scholars have attempted to examine which factors are associated with a state's decision to adopt the benefit. Using state-level data spanning 1992-2002, Kitchener et al. (2007) found four factors to be positively associated with the adoption decision: population age 85 and over, percentage nonwhite population, liberal state politics and Medicaid nursing home reimbursement rates. The two factors negatively associated with this decision were personal income per capita and hospital beds per 1,000 population.

The growth in the PCS program appears to be uneven over time. According to Litval and Kennedy (1991), the PCS option experienced a high rate of growth between 1984 and 1988 when the number of recipients rose by 65% and expenditures by 144%. In contrast, Kitchener, Ng and Harrington (2007) found that between 1999 and 2002, program participants adjusted for population increased by 27%. However, inflation adjusted program expenditures per participant did not keep pace and, in fact, declined by 3%. According to the authors, one explanation for a decline in expenditure relates to a marked decline in the range of services provided under the State Plan benefit, especially transportation.

In 1981, the introduction of 1915(c) waivers also led to changes in mechanisms for providing personal care services: personal care could now be offered through the PCS State Plan benefit and/or the HCBS 1915(c) waivers. In 1998-1999, 45 states offered at least some personal care in at least one HCBS waiver. The five states that did not offer personal care in their HCBS waiver maintained an optional PCS State Plan benefit. 25 states used only the HCBS waiver mechanism and 20 states used both programs (Le Blanc, Toner and Harrington, 2001).

Ruttner and Irvin (2013) compared service utilization and expenditures for personal assistance services in states that offer these services through a PCS State Plan (alternatively referred to as “State Plan” from here on) versus through 1915 (c) waivers alone. In order to ensure comparability and accuracy, the dataset only included 25 states. They found that when compared with states that offer PCS through waivers alone, State Plan states provide more access to personal assistance services as measured by the median proportions of Medicaid enrollees and HCBS users who use them. State Plan states also tend to spend less per-person, per-month on these services when compared with states that offer personal assistance through waivers alone. Finally, states that offer these services through their State Plans spend a higher median share of their LTC expenditures on HCBS than states that offer these services through waivers alone.

In practice, the two program features are often used as complements. Some states use the State Plan option to provide greater access to basic personal care services and then provide additional coverage through waiver programs to specific target populations. Alternatively, some states use the PCS benefit to provide services to those who do not have extensive functional impairments and therefore do not qualify for HCBS waiver programs. In addition, states use the PCS benefit to help individuals who are eligible for HCBS waiver programs but are waiting for an available slot in the program (Summer and Ihara, 2005; Weiner, Tilly, Alecxih, 2002).

Despite the prevailing claim that offering personal assistance services through the State Plan option leads to large increases in costs, recent studies on the “woodwork effect”<sup>10</sup> of HCBS provide contrary evidence. In an analysis of state-by-state Medicaid LTC spending for 1995–2005, Kaye, La Plante and Harrington (2009) find that states offering extensive non-institutional

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<sup>10</sup> Woodwork effect is a colorful term for induced demand. It has two components: 1) More people will use publicly funded services if access to HCBS is expanded and 2) The additional beneficiaries will increase the growth rate of Medicaid expenditures.

services experienced growth in overall spending comparable to that in states offering lower levels of such services. Similarly, Eiken, Burwell and Sredl (2013) also concluded that there is no strong evidence that increased funding for HCBS has led to an increase or decrease in total Medicaid LTC expenditure.

These results, however, are not based on multivariate regression methods and thus, do not provide a *ceteris paribus* effect of HCBS on Medicaid expenditures. Further, they examine the effect of HCBS spending in general and not the PCS State Plan option in particular. It is important to specifically investigate the effect of using the State Plan option because unlike 1915(c) waivers, that are also a part of a state's HCBS package, the State Plan instrument requires services to be provided state-wide to all eligibles who meet the functional need criteria. In other words, a state's HCBS offering is a patchwork of various instruments that can have differing effects on overall expenditure and these mechanisms should therefore be analyzed separately.

### 3.4 Methods

This paper examines the effect of adopting a PCS State Plan option on aggregate Medicaid expenditures. Towards this, I estimate the following fixed effect model:

$$M_{it} = \beta \text{StatePlan}_{it} + \lambda \text{Waiver}_{it} + \gamma Z_{it} + \alpha_t + S_i + \mu_{it} \quad (1)$$

where  $M_{it}$  is the level of Medicaid expenditures for state  $i$  at time  $t$ ;  $\text{State Plan}_{it}$  is an indicator for the presence of PCS State Plan optional benefit in state  $i$  at time  $t$ .  $\text{Waiver}_{it}$  is an indicator variable for the presence of a personal care waiver in state  $i$  at time  $t$ .  $Z_{it}$  is a vector of economic, demographic and political variables;  $\alpha_t$  is a time-specific intercept (a vector of year dummy variables);  $S_i$  is a state-specific intercept (a vector of state dummy variables); and  $\mu_{it}$  is a mean zero random error.



The results reported here are based on a semi-log model in which  $M_{it}$  is the natural log of expenditures in a given state and year. The state fixed effects capture all factors that are specific to a particular state and remain largely invariant over time. Such variables may include basic political and religious sentiments, and geographic characteristics. The year fixed effects capture factors that are common across all states in a particular year, such as federal policies (for example, the Omnibus Budget Reconciliation Act (OBRA), 1981 that authorized the waiver program) and major US Supreme Court decisions (for example the *Olmstead* ruling in 1999 that gave HCBS services a big push). Thus, the basic identification strategy implicit in this fixed effects approach purges the unobserved and potentially confounded cross-sectional heterogeneity by relying on within-state variations in PCS State Plan adoption over time, and by using those states that did not face changes in PCS State Plan adoption as a control for unrelated time-series variation. Robust standard errors are clustered by state.

### **3.5 Data**

The data used in this paper were collected from a variety of secondary sources. I describe these sources in detail below. Table 3-1 provides descriptive statistics for all variables.

#### **3.5.1 State Medicaid Expenditures**

Aggregate Medicaid expenditures for each state were collected for the period 1975 through 2009. The time series begins in 1975 because the option to provide PCS through a State Plan was first made available that year.

In particular, I obtained Medicaid expenditures for each state for the period 1980-2009 from the National Health Expenditure data provided by Centers for Medicare and Medicaid Services (CMS, 2015a). Medicaid expenditures for 1975 were extracted from a report prepared for the Committee on Interstate and Foreign Commerce (U.S. Congress, 1977). Medicaid

expenditures for 1976-1977 were extracted from reports prepared by Institute of Medicaid Management (Institute of Medicaid Management/U.S. Department of Health, Education and Welfare, 1978, 1979). Finally, for 1979, state-by-state aggregate Medicaid expenditures were taken from an evaluation of the program conducted by the Urban Institute (Holahan, 1986). Because expenditure data for 1978 was unavailable from online sources, I averaged the 1977 and 1979 numbers for each state to obtain approximate 1978 values.

With 51 states spanning 35 years, there should ideally be 1785 observations. However, as Arizona did not have a Medicaid program for LTC for the first seven years of the study, there are a total of 1778 observations. All monetary values are in constant 2009 dollars and measure aggregate expenditure regardless of the share paid from state funds.

### **3.5.2 PCS State Plan option**

Information on the presence of PCS State Plan Option across states was obtained from three sources: Simi and Litval (1991); Le Blanc, Tonner, and Harrington (2001) and Data updates on the Medicaid Home and Community Based Service Programs from the Kaiser Family Foundation (2011).

Figure 3-1 shows a map of all adopting and non-adopting states by decade of adoption. Most states that eventually adopted the program did so by 1990. There appears to be a slight geographic clustering among non-adopters in the mid-west and southern parts of the country. Figure 3-2 presents the cumulative number of states with a PCS State Plan option in each year for the 1974-2009 period. The number of states with a PCS State Plan increased steadily from 1975 until the late eighties.<sup>11</sup>

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<sup>11</sup> Delaware and Rhode Island were approved by CMS to offer personal care through their State Plan in 1999. However, it appears that they haven't yet utilized the instrument because neither of the two states have ever reported any participants or expenditures for their PCS State Plans. For the purposes of this study, I code them as non-adopters.

As indicated in Figure 3-1 and Figure 3-2, in the 1990s, very few states adopted the State Plan option. This number began to grow again after 1999, before starting to flatten in 2007. Kansas became the latest state to adopt the PCS State Plan benefit in 2007. No new state has adopted the program since then. In addition, no state has dropped the PCS benefit from their Medicaid State Plan after having adopted it in a previous year. In 2009, a total of 32 states had adopted the PCS State Plan option. For the analyses in this paper, the PCS State Plan benefit is captured by an indicator variable which equals 1 if PCS State Plan benefit is present in a particular state during a certain year, and 0 otherwise.

### **3.5.3 1915(c) waivers offering personal care**

Beginning in 1981, states could provide personal care services through 1915(c) waivers. Because waivers are more flexible and allow easier targeting of benefits, some scholars have argued that states are increasingly relying on waiver programs to offer personal care services instead of adding the benefit to their State Plan (O’Keeffe, 2010). Further, it is likely that the correlation between waivers and Medicaid expenditures is not equal to zero. Thus, in order to avoid an omitted variable bias, it is important to control for the presence of a personal care waiver in a given state.

Data on personal care waivers was obtained from the CMS website (2015b), which lists all waivers offered by every state. It also provides a description of each waiver, including the program’s approval date. States with waivers that included “personal care” or “personal support” services in the description were coded to have a personal care waiver. The approval date of the waiver was used as the start date of the program in the dataset. To ensure comparability of services between waivers and the State Plan option, those waivers that only included “homemaker” or “chore services” were not coded as personal care waivers.

Figure 3-3 overlays the evolution of personal care waivers on PCS State Plan adoption. The graph indicates that by the late 1980s, the number of states offering personal care in at least one HCBS waiver grew rapidly. After 1987, the number of states offering personal care through waivers was more than the number of states that had adopted PCS State Plan option. At present, almost all states offer personal care through at least one active HCBS waiver.

It is important to acknowledge that accurate data on HCBS waivers is notoriously difficult to collect because states often submit numerous amendments to their waiver programs. As a result, a state's waiver portfolio can change considerably over time. The CMS website does not record these year-to-year changes in the description of waivers. To ensure accuracy of personal care waiver start dates, I corroborate the CMS data with that provided in Le Blanc, Tonner and Harrington (2001). This study details the presence of personal care waivers across all states during an earlier time period (1997-1999). While some errors may still remain, it would be prohibitively expensive to gather all the information required to assess the complexity of every state's program, especially over time. Further research will be necessary to determine how variation in the design, implementation and oversight of 1915(c) waivers relates to these current findings.

#### **3.5.4 Other Control Variables**

The empirical model controls for a series of political, economic and demographic variables likely to influence Medicaid expenditures. The political variables include an indicator for whether the state's governor belonged to the Democratic Party. This was information was taken from the National Governors Association (2015). Additionally, to capture state generosity, I control for two other policy variables: 1) whether the state had a Medically Needy option<sup>12</sup> and,

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<sup>12</sup> In some states, those individuals who do not meet a state's income and asset eligibility limits may still qualify for Medicaid if they have significant medical expenses that reduce their income below a certain level, through what are

2) the amount of state supplement to the federal SSI benefit (in 2009 dollars).<sup>13</sup> The data on the medically needy option across states is provided by David Grabowski from Harvard University (2013). State supplementation of SSI payments for 1975-1995 are gathered from Ponce (1996). Thereafter, information on this variable is taken from Urban Institute's TRIM3 database (2012). Because these three political variables capture the construct of state generosity, it is expected that all three will lead to an increase in aggregate Medicaid expenditures.

The economic variables include average state income (in 2009 dollars) and state unemployment rate. The state income is obtained from the Department of Commerce, U.S. Bureau of the Census (2015), and the state unemployment rate is obtained from the Bureau of Labor Statistics (2015). Higher incomes and lower unemployment rates may reduce the number of people eligible for Medicaid and thus, decrease Medicaid expenditures. On the other hand, some studies have also demonstrated that states with higher personal income tend to be more generous in their funding of Medicaid HCBS programs (Kane et al., 1998). Therefore, the direction of the effect is difficult to predict.

The demographic variables cover a state's total population and the proportion of elderly population (above age 65). Both these variables are obtained from the U.S. Bureau of the Census (2015). A large population suggests a greater number of eligible residents and therefore a higher level of Medicaid expenditures. Because LTC expenditures are a substantial part of overall Medicaid expenditures, a large elderly population is also expected to increase overall Medicaid expenditures.

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called "medically needy" programs. All states have the option of covering so-called medically needy individuals, but not all do.

<sup>13</sup> SSI or Supplemental Security Income is a federal program that provides monthly cash payments to people in need. Some states add money to the federal benefit and this is known as state supplementation of SSI benefit.

### 3.6 Results

Estimates from the fixed-effects regression are provided in Table 3-2. Overall, the results indicate that, at most, the adoption of PCS State Plan had a weak effect on aggregate Medicaid expenditures. While coefficient on PCS State Plan variable was positive, there was no statistically significant effect of PCS State Plan adoption on aggregate Medicaid expenditures. Further, even the statistically insignificant effect suggested a less than 5% increase in expenditures as a result of PCS State Plan adoption over the entire 35-year period.

Turning briefly to other variables in the regression, I find that the presence of a personal care waiver leads to a decrease in Medicaid spending, though the effect is not statistically significant. It is possible that HCBS waivers reduce the number of individuals in nursing homes, thereby leading to a decrease in nursing home expenditures which still account for the largest share in overall Medicaid LTC expenditures. However, because the coefficient is not statistically significant, it is difficult to interpret the results substantively.

A larger proportion of population age 65 and older was associated with higher Medicaid expenditures. Specifically, a 1% increase in this proportion was associated with a 0.79% increase in Medicaid expenditures. A larger population and a higher unemployment rate was also associated with an increase in Medicaid expenditures. The remaining variables in the model were not statistically significant.

These findings were robust to a number of alternate model specifications (all robustness checks are available on request). First, it could be argued that there is some lag between PCS State Plan adoption and Medicaid expenditures. To test this argument, I ran versions of the model with one-period and two-period lags of the PCS State Plan variable included. Adding these lags had little effect on the PCS coefficient.

Second, unobservable characteristics in a state might change over time in ways that differ across states. Such characteristics could include changing demand for HCBS in a state. To test for this, I ran the model including state-specific linear time trends. This allows one to control for a slowly evolving change in tastes for HCBS across states. Including this control had no effect on the coefficient on the PCS variable.

### **3.6.1 Effect of PCS State Plan over time**

The period 1975-2009 represents more than four decades of Medicaid HCBS evolution. To investigate how the effect of adopting PCS State Plan benefit on Medicaid expenditures changed over time, I interact the PCS State Plan variable with year dummies. I include the interactions as well as the main effects in the regression model. As in the previous case, robust standard errors are clustered by state.

In this specification, the coefficient on the State Plan indicator (main effect) represents the effect of PCS State Plan in the baseline year (1975). To get the effect of PCS State Plan on Medicaid expenditures for subsequent years, I add the coefficient on the main effect and the coefficient on each State Plan–year interaction. Because this time series spans 35 years, I present the year-by-year effect of having a PCS State Plan on Medicaid expenditures in a graphical format (see Figure 3-4).

The figure illustrates that for a brief period in the early years, the adoption of a PCS State Plan led to a statistically significant increase in aggregate Medicaid expenditures. Specifically, electing to cover personal care through a State Plan led to an as much as 20% increase in Medicaid expenditures in 1975 and 1982. Towards the end of 1980s, the effect of PCS State Plan began to decrease. After 1993, there was appears to be no effect of PCS State Plan on Medicaid

expenditures. This suggests that the overall positive effect of PCS on Medicaid expenditures mainly represents the effect of the program in the early growth years.

The diminishing effect of PCS on Medicaid expenditures may be a result of a number of key changes that took place during the 1990s. These events are known to have markedly altered the Medicaid HCBS landscape in general. First, though initially introduced in 1981 under OBRA, it was the presidential administrations of Bill Clinton and George W. Bush that saw an outpouring of 1915(c) waivers (Thompson and Burke, 2007). After waivers were introduced in the 1980s, officials were worried that states might use the 1915(c) instrument to open floodgates to greater Medicaid expenditures. To avoid that, the Office of Management and Budget imposed the “cold-bed” rule in the mid-1980s. This rule required states to demonstrate that for each HCBS waiver participant, it had emptied an institutional bed. As a result, states found it difficult to submit ambitious waiver proposals (Shirk, 2006).<sup>14</sup> The Clinton administration ushered in a more hospitable climate for Medicaid waivers by eliminating the cold-bed rule (Thompson and Burke, 2007) in 1994, which consequently led to a rapid expansion of the program.<sup>15</sup>

Second, as described above, starting in 1993 Congress made several revisions to the PCS State Plan benefit itself. As a result of these changes made in federal policy, Keeffe et al. (2010) note that there remained little difference in the scope of personal care services that could be offered under the Medicaid State Plan and those that may be offered under an HCBS waiver.

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<sup>14</sup> According to Thompson and Burke (2007), during the 1980s, states often found negotiations with the federal bureaucracy over waiver approval to be arduous and protracted. For instance, it took Minnesota officials four years to obtain a federal sign-off on an HCBS waiver proposal, and Texas administrators three years. Delay frequently stemmed from differences between national and state officials over how to estimate the costs of the waiver.

<sup>15</sup> The growth in HCBS waivers during the 1990s does not contradict the graph presented in Figure 3-3. It is important to keep in mind that Figure 3-3 presents information on states having at least one HCBS waiver that offered personal care, and not the total number of waivers over time.



Thus, it is possible that with a rapid expansion of HCBS waivers in general, and the increasing degree of substitutability between waivers and the State Plan (in terms of the nature of services that could be offered through the two instruments), officials were able to combine the two options in such a way that the delivery of personal care through the State Plan vehicle became less expensive.

This shift away from the PCS State Plan is evidenced in the literature as well. Between 1992 and 2002, 1915(c) waiver program spending increased from 37% to 67% of the total Medicaid HCBS spending. On the other hand, spending for the PCS State Plan benefit dropped from 22% of total HCBS spending to 11% of total HCBS spending (Reester, Missmar and Tumlinson, 2004). Previous studies also suggest some decline in the services provided by states in their PCS State Plans. For example, from 1984 to 1988, there was a reduction in the number of states that provided respite and emergency services (Litval and Kennedy, 1991). In 1991, Michigan was known to have dropped from the program people who received purely chore services because they were solely state funded (Litval and Kennedy, 1991). Similarly, from 1999 to 2002, the number of states that provided transportation services in their PCS State Plans also reduced (Kitchener, Ng and Harrington, 2007). There is also evidence that by 1988, fewer states had round-the-clock availability of personal care attendants (Litval and Kennedy, 1991). In addition, in 1984, about 70% of the PCS State Plans had specified service limits (cost or hourly caps) – by 1999, this number had changed to over 90% (Litval and Kennedy, 1991; Kitchener, Ng and Harrington, 2007). While a dummy variable approach to represent different PCS programs is useful in a study like this, further research needs to be carried out on how the content and design of these programs has changed over time.

### **3.6.2 Heterogeneous behavior in PCS State Plan adoption**

An important area of research in political science focuses on understanding the diffusion of policies across states. While most studies of this nature attempt to model whether the timing of policy adoption in a state is influenced by the policy adoption behavior of its neighbors, the theoretical mechanisms behind such adoption processes remain largely understudied (Hays and Glick, 1997; Mintrom, 1997).

Diffusion theory is assumed to be based on a social learning process (Mooney, 2001). Social learning theory posits that state officials tend to draw on experience of other states (not necessarily neighboring states) when considering the adoption of a new policy. Information learned from another state can either enhance or diminish the chances of a polity adopting a law (Mooney, 2001). In other words, depending upon the policy, information learned from another state could have positive or negative effects on own adoption behavior.

In this context, officials may find it relevant to learn from adopting states' experiences on the effectiveness and efficiency of using the State Plan instrument to provide personal care services. That said, it is challenging to learn about effectiveness as state aggregate data on HCBS programs, participants, policies and outcomes are generally unavailable. One reason for this is that CMS does not have uniform reporting requirements across different HCBS programs (Harrington et al., 2009). On the other hand, states may find it relatively easier to learn from others on cost implications of adopting a PCS State Plan as expenditure data are widely available.

If social learning plays a role in the diffusion of PCS State Plan adoption, then it is hypothesized that states attempt to predict changes in own expenditures based on the experience of other states, and decide to adopt the policy only if the predicted costs of doing so are low.

While there are many examples of states conducting feasibility studies before adopting a new policy, it is unclear if they use the experience of others states in this process.<sup>16</sup>

In this section, I provide descriptive evidence on whether states display behavior that concurs with the theory of social learning. If, before making the decision to adopt a State Plan, states could predict cost changes associated with a hypothetical adoption (based on the experience of other states as well as their own characteristics), and if these predicted costs varied consistently with the eventual decision to adopt or not-adopt (that is, states with higher predicted costs were less likely to adopt in the future), then this represents suggestive evidence that states make policy decisions based on information that is gleaned from peers and adapted to their own situations.

To do this analysis, I interact all control variables in equation (1) with the indicator variable for PCS State Plan. This enables each state to have a PCS State Plan-associated cost component that varies with individual state characteristics. I include all interactions and main effects in the model and save predicted expenditures from the fitted regression (Table 3-3).

Next, I focus on all non-adopting states across different years. For these states, I save the predicted values from the above regression as “original predicted expenditure.” To impute the effect of a hypothetical State Plan adoption among these states, I change the value of the State Plan indicator variable from 0 to 1 and then re-calculate predicted expenditure using information from the same fitted regression. These new values of predicted expenditure are saved as “hypothetical predicted expenditure.” This represents predicted expenditures in a scenario where non-adopters hypothetically adopted a PCS State Plan.

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<sup>16</sup> Iowa is an example of a state that does not have a Personal Care Medicaid State Plan Option. They did an extensive study with recommendations to add the service but ultimately found the cost was too high (American Public Human Services Association/Center for Workers with Disabilities, 2006)

For these non-adopting states, I then calculate the difference between “hypothetical predicted expenditure” and “original predicted expenditure.” This difference is the “*price*” of PCS State Plan adoption to a non-adopting state in a given year. Next, I create a variable to indicate whether a state eventually adopts the PCS State Plan.

Figure 3-5 illustrates the average “cost” of the PCS State Plan adoption among states that never adopt and those that are current non-adopters but eventually go on to adopt. The figure shows that during the 1980s, when having a PCS State Plan led to an increase in Medicaid expenditures, current non-adopters that never adopted the State Plan had a higher average cost of adoption in all years of the decade. In contrast, those non-adopters that eventually adopted the State Plan had lower average cost of adoption in all years of the decade.

In other words, it is likely that states that never adopt the Plan do so because they face a high price of PCS adoption. Similarly, current non-adopters that eventually adopt do so because they face a relatively lower price of PCS State Plan adoption. This behavior appears to be consistent with the theory of social learning.

### **3.7 Conclusion**

Though previous literature has claimed that adopting a PCS State Plan is likely to lead to large increases in spending, no study has empirically examined this question using longitudinal data. This paper represents the first effort to investigate the effect of the program on Medicaid expenditures from 1975 through 2009. It is also the first study that analyzes the development of the PCS State Plan since its inception in 1975 until 2009.

I find that the adoption of a PCS State Plan led to an increase in Medicaid expenditures only during the early growth years of the program in the 1980s, and that this effect diminished over time. Specifically, averaging over the entire time period, as well as in individual recent

years, there is no statistically significant effect of PCS State Plan adoption on Medicaid expenditures. While high administrative costs may have contributed to an increase in expenditures during the early years of program implementation, the growth of 1915(c) waivers during the late 1980s and the 1990s likely played a role in enabling state officials to adapt by directing State Plan services and participants to waiver programs. A few scholars also note that there is less reason to be concerned about runaway spending because Medicaid's financial eligibility test – in particular the \$2,000 asset limit in nearly all states – is particularly restrictive and has not been raised in nearly three decades. In other words, the restrictiveness of the asset test limits the number of people who can gain eligibility into the program (Borck et al., 2014).

In general, the main message of this study is that over time, state officials have been able to adjust design elements of an entitlement program (within the constraints of the Medicaid law) in such a way that it no longer influences overall expenditures. While this is positive news from a spending perspective, it does raise questions about the ability of the program to meet LTC needs of the population in its current form. Systematic evaluations of recipient outcomes need to be conducted to examine this question in greater detail.

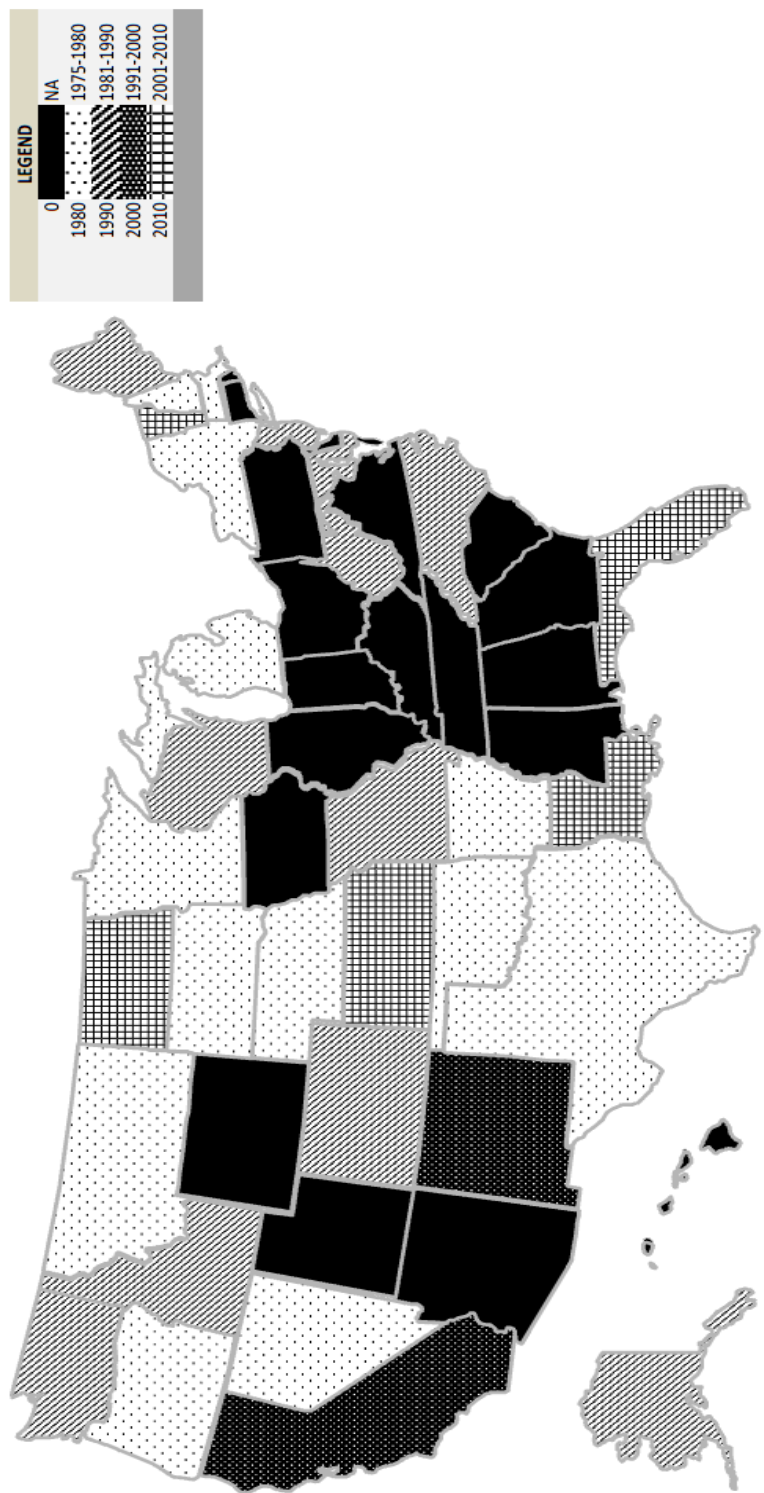
I also find suggestive evidence that states potentially learn from the experience of other states in order to make their own adoption decisions. In particular, non-adopting states that were predicted to have high costs of a hypothetical PCS adoption were less likely to adopt the benefit in the future as compared to those non-adopters that were predicted to have relatively low costs of such an adoption.

A key limitation of this study is that a variety of secondary sources were used to collect information on Medicaid expenditures. This raises the possibility of measurement error which

can cause estimates to shrink towards zero. To the extent possible, future studies should attempt to collect data from unified sources.

As the American population ages, the demand for LTC services is expected to surge. However, potential cost implications have remained a key stumbling block in the development and expansion of publicly provided formal care services like personal care. Targeted future research on the efficiency and quality of such programs needs to be conducted in order to gain a better understanding of how states tailor LTC services under the constraints of budgets, federal rules and state-specific policy objectives.

Figure 3-1 : PCS State Plan Adoption in the U.S.



*Table 3-1 : Descriptive Statistics*

State Level Variables	Mean	S.D
Total Medicaid Expenditure (millions of 2009 \$)	3257	5440
PCS State Plan (Yes=1, No=0)	0.44	
1915(c) waiver that offered personal care (Yes=1, No=0)	0.57	
Democratic governor (Yes=1, No=0)	0.55	
Medically needy (Yes=1, No=0)	0.69	
State supplement to SSI (2009 \$)	53.61	104.58
Personal per capita income (1,000s 2009 \$)	29.06	9.3
Unemployment rate (percent)	5.97	
Total Population (millions)	17.9	81
Percent 65 and above	11.20%	



Figure 3-2 : Cumulative Number of States with PCS State Plan

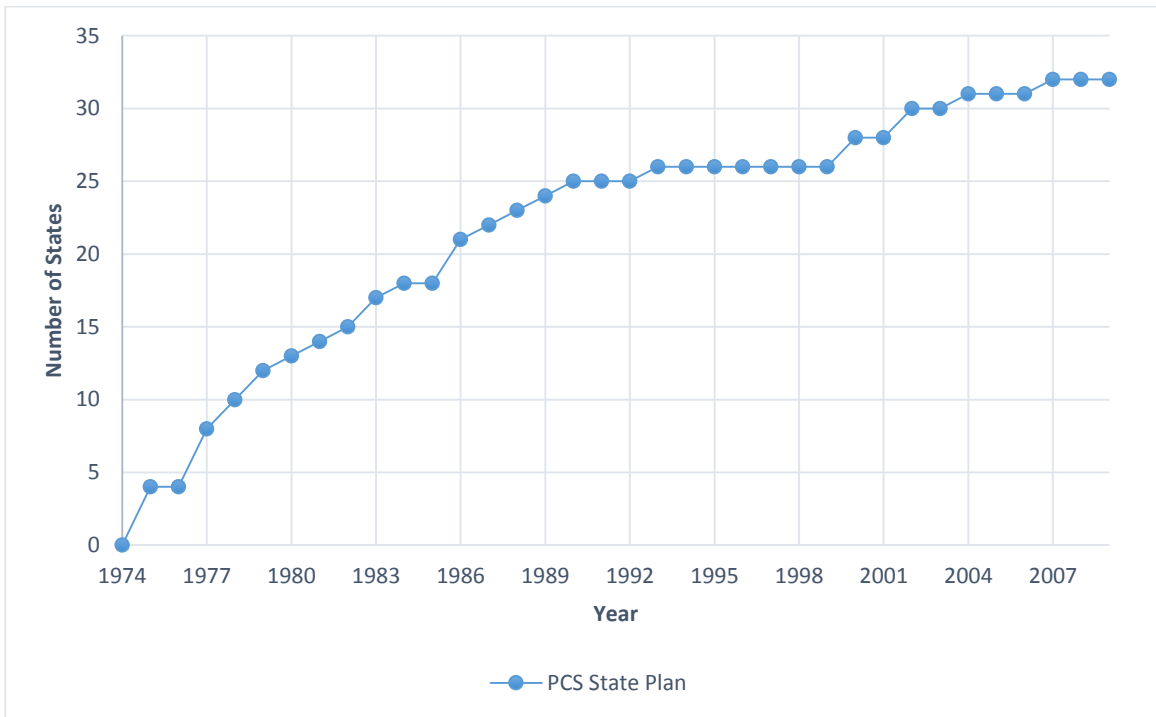
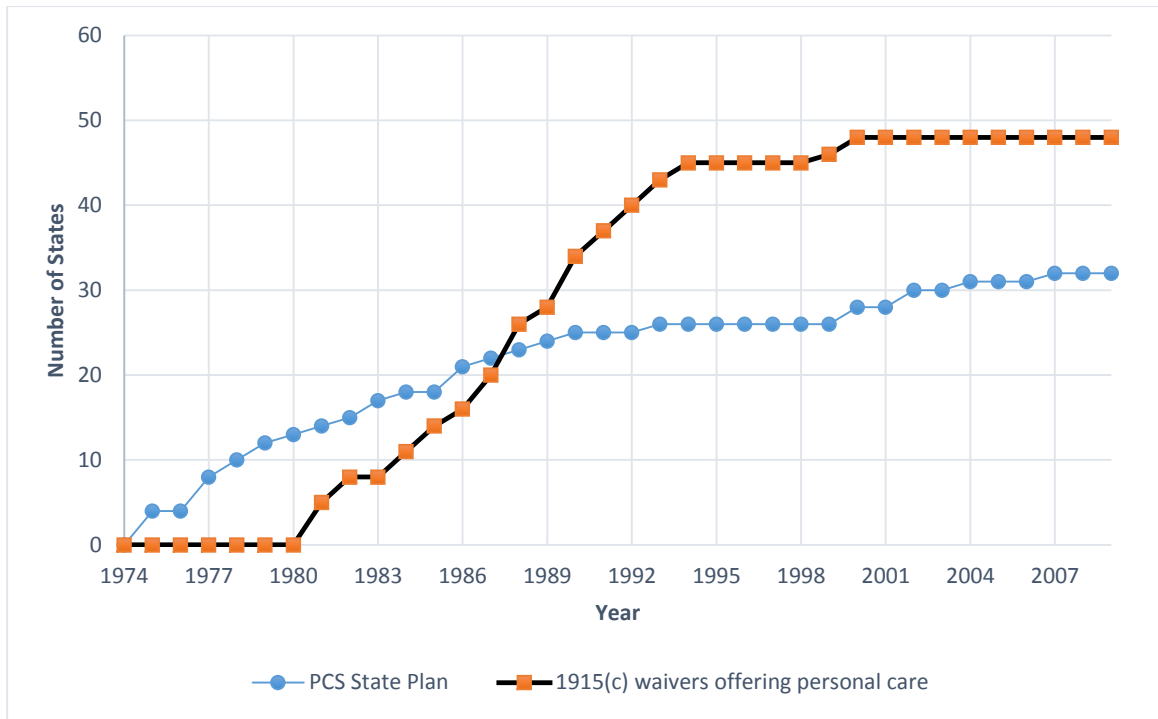


Figure 3-3 : Cumulative Number of States with PCS State Plan & 1915(c) waivers that provide personal care

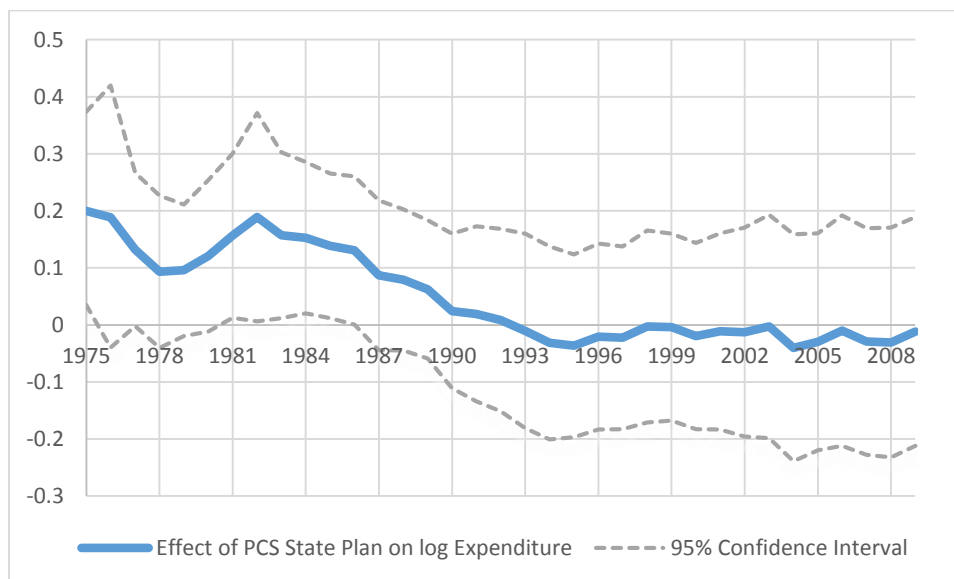


*Table 3-2 : Effect of PCS State Plan on Medicaid Expenditures*

	Ln Medicaid Expenditures	
PCS State Plan Adoption	0.04	(0.06)
1915(c) waiver with personal care	-0.07	(0.06)
Ln total population	0.76	** (0.19)
Ln % population over 65	0.78	** (0.18)
Ln per capita income	0.32	(0.25)
Ln unemployment rate	0.1	* (0.04)
Medically Needy	0.06	(0.07)
State supplement to SSI	0.0005	(0.00)
Democratic Governor	0.01	(0.01)
Constant	-9.17	(4.49)
State Fixed Effects	Yes	
Year Fixed Effects	Yes	
<i>N</i>	1778	

Notes: Robust standard error cluster by state in parentheses. \* Statistically significant at 5%;  
 \*\* Statistically significant at 1%

Figure 3-4 : Effect of PCS State Plan on Expenditures Over Time

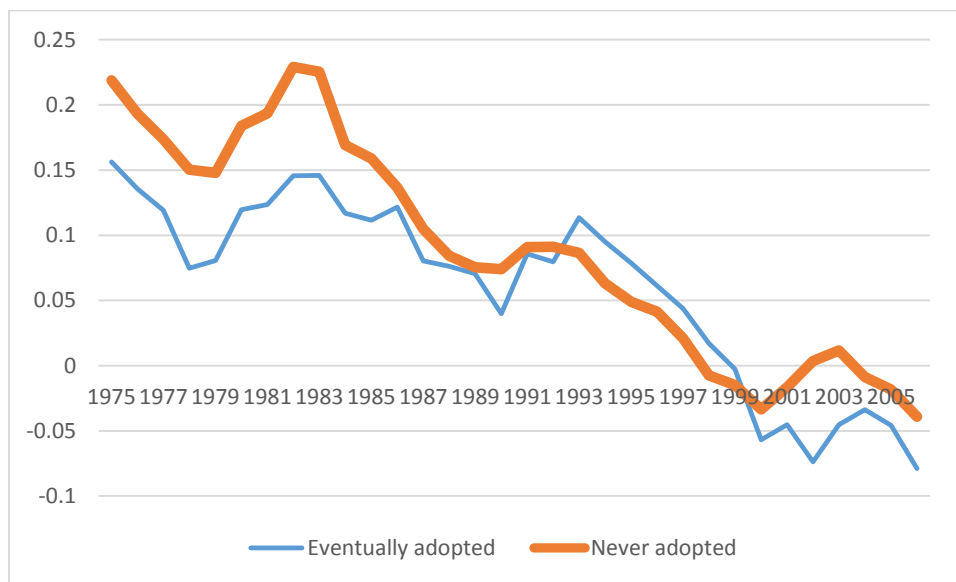


*Table 3-3 : Fixed Effects Regressions with Interactions*

	Ln Medicaid Expenditures	
PCS State Plan Adoption	2.73	(1.33)
1915(c) waiver with personal care	0.01	(0.08)
Ln total population	0.77	(0.22)
Ln % population over 65	0.78	(0.22)
Ln per capita income	0.30	(0.27)
Ln unemployment rate	-0.07	(0.06)
Medically Needy	0.07	(0.08)
State supplement to SSI	0.00	(0.00)
Democratic Governor	-0.02	(0.03)
PCS*1915(c) waiver with personal care	0.06	(0.10)
PCS*Ln total population	0.28	(0.17)
PCS*Ln % population over 65	0.25	(0.17)
PCS*Ln per capita income	-0.32	(0.18)
PCS*Ln unemployment rate	0.12	(0.08)
PCS*Medically Needy	-0.22	(0.08)
PCS*State supplement to SSI	0.00	(0.00)
PCS*Democratic Governor	0.05	(0.04)
Constant	-9.13	(4.48)
State Fixed Effects	Yes	
Year Fixed Effects	Yes	
<i>N</i>	1778.00	

Notes: Robust standard error cluster by state in parentheses. Other control variables: PCS State Plan interactions with years dummies

Figure 3-5 : Cost of PCS Adoption for Non-Adopting states



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- Graduate Associate Award, Maxwell School, Syracuse University 2010-2012
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- Member, Pi Alpha Alpha, National Honor Society for Public Affairs and Administration 2007
- Cornell Urban Scholars Award 2006
- Cornell Institute of Public Affairs Fellowship 2005-2007

## TEXTBOOK

Trochim, W.M., Donnelly, J. and **Arora, K.** (2015 – In Press). *Research Methods: The Essential Knowledge Base*. Belmont, CA: Cengage Learning

## PUBLICATIONS

- **Arora, K.** and Wolf, D.A. (2014) “Is there a Tradeoff between Parent Care and Self Care?” *Demography*. 51 (4) 1251-1270
- **Arora, K.** and Trochim, W.M. (2013). “Rating Systems in International Evaluation.” *i-eval Think Piece*, No. 3. International Labor Organization

## WORKING PAPERS

- **Arora, K.** “How Does Dementia Onset in Parents Influence Adult Children’s Wealth?” [Under Review]
- Wolf, D.A. and **Arora, K.** “Do State-Level Policy Choices Influence Caregiver Behavior?”

## MANUSCRIPTS IN PREPARATION

- **Arora, K.** “Predictors of State Adoption of Medicaid Personal Care Services (PCS) Benefit Option”
- **Arora, K.** and Trochim W.M. “Using Network Theory to Enhance Program Evaluation”



## CONFERENCE PRESENTATIONS

### Papers

- “*An Algorithm-Based Approach to Enhance Program Theory Articulation*” Oct, 2014  
American Evaluation Association, Denver, CO
- “*Do State-Level Policy Choices Influence Caregiver Behavior*” Nov, 2013  
Southern Economics Association, Tampa, FL
- “*Evaluating the Quality of Visual Causal Modeling*” Oct, 2013  
American Evaluation Association, Washington, DC
- “*Caregiving and Physical Activity: Competing Time Choices?*” Apr, 2013  
Population Association of America, New Orleans, LA
- “*Enhancing the Quality of Rating Systems in International Evaluation*” Oct, 2012  
American Evaluation Association, Minneapolis, MN
- “*Incorporation of Systems Thinking in Evaluation Practice*” Nov, 2011  
American Evaluation Association, Anaheim, CA

### Posters

- “*Parent’s Dementia Onset and Change in Adult Children’s Wealth*” Nov, 2014  
**Third Prize** at APPAM Poster Session, Albuquerque, NM
- “*Parent’s Long-Term Care Needs and the Economic Status of Adult Children*” May, 2014  
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## TEACHING EXPERIENCE

*Introduction to Statistics* (Graduate-level) Fall 2012 and Fall 2013  
Guest Lecturer, Maxwell School, Syracuse University

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