

## POLICY PAPER

# Informal Cost of Dementia Care – A Proxy-Good Valuation in Ireland

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*Abstract:* This paper values the informal costs of dementia care in Ireland based on recently agreed national costing framework. Drawing on a survey of 270 Irish dementia caregivers, the hours of informal care per day are estimated using variables of individual characteristics, functional limitations and behavioural problems. This estimation finds that an interlinked work-cohabitation effect significantly predicts the total informal care available and suggests that increasing burden on carers may alter overall welfare. Given conflict in carers' personal priorities, this paper calculates the market value of formal services to inform equitable distribution of dementia care required. By associating 'proxy-good' market values to dementia symptoms requiring specific types of care, the *per diem* costs of care are estimated to range from €240.96 (early-stage) to €570.04 (late-stage). As burnout is a major risk factor in prolonged care, this paper indicates the formal value of the output of care from a public health service perspective. Policy initiatives to improve technical and allocative efficiency of formal dementia services are required to reduce reliance on informal care.

## I INTRODUCTION

The economic burden of dementia ranks higher than stroke, heart disease and cancer combined (Lowin *et al.*, 2001), however, Ireland spends approximately half the OECD average on dementia care (Trepel, 2010). As the model for dementia care has shifted towards community care (Brown, 1985,

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Morrissey and Goldman, 1984), greater demand has been placed on the informal sector. The formal service costs offset by care provided informally is substantial, but over reliance poses various risks such as carer's productivity loss (Koopmanschap *et al.*, 1995) and care giver burnout (Almberg *et al.*, 1997).

Informal care can be defined as the production of commodities (such as providing basic nutrition, household maintenance, personal care and safety) which maintain the household unit. Dementia's progressively incapacitating nature increases carers' likelihoods of experiencing diminished personal, physical, mental, social and/or financial welfare. Therefore, informal care in dementia may be appropriately defined as "... the dutiful act of basic concern given an anticipatable lower yield of personal welfare" (Sen, 1997).

The policy perspective adopted when valuing input to care determines the cost associable to care (Drummond *et al.*, 2005) and subsequent budget allocations. As informal care often accounts for a substantial proportion of the total cost of dementia, a long-standing debate over valuation methods for informal care exists (McDaid, 2001, Koopmanschap *et al.*, 2008). Variability of these estimates is driven in part by national idiosyncrasies in funding mechanisms and the economic perspective prescribed by local guidelines. Previous Irish estimates employed contingent valuations by willingness to pay (valuing one hour of informal care in 2000 between £2-£4) (O'Shea and O'Reilly, 2000), although this is not strictly the cost of informal care, but the individual's valuation offset against the costs of care (Wimo *et al.*, 2002).

To ensure that valuations of informal care are equitable across varying disease types, comprehensive valuations should consider the opportunity cost of losing human capital, the overhead costs of providing care and the value a carer would attribute to their time lost. One should consider the stock loss associated with the competences, knowledge and personality qualities reflected in the individual's human capital (Becker, 1993). In application, measuring the opportunity cost of foregone earnings provides a measure of the human capital loss, however, it is argued that this loss of earnings resulting from providing care is transient. As a solution, the "friction cost" method proposes a refinement of the opportunity cost measuring the transient absenteeism (Koopmanschap *et al.*, 1995).

Contingent valuation using willingness-to-pay (WTP) analysis is often applied in evaluation of health interventions to calculate a cost benefit ratio forming a relationship to the social welfare function. Sen (1997) critiques this type of approach stating that eliciting a valuation through WTP may not be meaningful since the value of money will vary between individuals. More recently, theory suggests that WTP does not also capture a "process utility" in which a carer derives a utility gain from care (Brouwer *et al.*, 2005).

Health economic evaluation has widely adopted Sen's extra-welfare perspective and decision models for resource allocation commonly centred on the cost per quality adjusted life year (QALY). QALYs position health as the maximand in a social welfare function replacing a general utility function. In application, the extra-welfare framework tends to focus on direct healthcare costs required to improve the health state but maximisation of health may not consider wider societal costs and utilities, such as informal care.

The proxy-good valuation method applies shadow pricing in producing dementia-specific outputs of care. By taking the total health service staff cost as units of care output, this framework captures the value of the opportunity cost associated with human capital, overhead costs and captures a point of indifference substituting informal care for formal services. Since the informal time lost in accepting the duty of care is equal to the formal services gain through averted burden of care, the proxy-good valuation represents a socially optimal solution to valuing informal care.

The *Health Information and Quality Authority* (HIQA) published economic evaluation guidelines in 2010 which delivered a formal framework for calculating the proxy-good values (HIQA, 2010, p. 27). Under these guidelines, health care decision makers are advised to primarily focus on direct costs specific to the public health care budget but, this perspective may result in a default view that indirect costs such as informal care are a "free resource". To counteract this potential pitfall of underestimating the total cost of dementia, this paper associates a cost to informal care by applying proxy-good values in the Irish health service. This forms a compromise between the direct and societal viewpoint by building in the informal carer's productivity loss and overhead costs whilst applying a value to the specific outputs of dementia care through the Irish formalised costing framework.

Regression analysis of 270 Irish informal dementia carers is used to estimate the hours of informal care based on individual characteristics, functional limitation and behavioural problems. Individual characteristics, such as age, stage of disease and employment/cohabitation status, have previously been found to have health and social consequences for the carer (Grafström *et al.*, 1992). Dementia is one of the strongest causes of functional dependence (Aguero-Torres *et al.*, 1998) and the impact of limitations on carers is measured using various activities of daily living. Psychiatric symptoms often motivates supervision time to avert dangerous events and manage behavioural disturbances, such as aggression or wandering (Wimo *et al.*, 2002).

The model predicts informal care time per day required for specific symptoms of dementia at each stage. To these predicted outputs of care, specific proxy market values of the associable formal management of dementia

symptoms are applied. This calculates the cost of replacing all outputs of informal care and indicates the financial risk of losing carers to burnout. Previous reviews of informal care have argued that a full replacement value would ignore routinely provided household duties not related to dementia care (McDaid, 2001). To indicate the dementia specific increment over these routine outputs, the proxy-good method attributes values to dementia specific variables (such as ADLs and behavioural problems). This indicates at each dementia stage, the specific output which necessitates care and excludes prior household responsibility by holding them in the equation's error term.

Regression analysis indicates that individuals who receive training to provide informal care exhibit a substantial reduction in burden of care and increasing training may facilitate sustainability of their role. The combination of employment/cohabitation status are found to highly influence the level of care provided and is an important consideration in deploying formal resources. These results, and the associated informal cost of care, present an argument for allocative efficiency with respect to informal provisions and show the need for greater consideration in priority setting when budgeting for competing disease (e.g. stroke, heart disease and cancer). As such, the proxy-good method provides a compromise between direct and societal valuation that may be uniformly applied in future health economic evaluations in Ireland.

The next section will describe the salient dynamics of dementia care. Section III presents the survey and descriptive statistics used to validate the empirical model. Section IV applies a Tobit model to estimate daily informal care time and examines the individuals' functional and behavioural effects associated with these predictions. Section V draws conclusions on the findings and offers policy recommendations.

## II DYNAMICS OF CARE

To explain the motivation for this study, this section presents the dynamics of dementia care and how, in the absence of appropriate regulation or legislation, the majority of burden will fall on informal carers.

Demand for care in dementia ranks highly compared to other diseases (Murray and Lopez, 1996). Demand is correlated to progressive cognitive, functional and behavioural impairment (Angermeyer *et al.*, 2006). As decline is generally irreversible, individuals tend towards a state where they are completely dependent on care.

Dementia care is defined as a game consisting of three players; one formal agent (a provider in the health, social or voluntary sectors), an informal carer (family, friends or the general community) and one recipient with dementia. In

a perfect world, all care providers would be observed to allocate their optimal amount of time to their recipient, forming a market equilibrium in which the utility gain from providing care is optimal without reducing the carer's profits. The combination of caregivers' actions enhances the recipient's health and utility level through the care received. The social welfare in this system would be maximised where there is perfect information transfer between all agents.

Such a first best equilibrium depicts an ideal situation which ignores many nuances of reality where the production of care outputs by either formal or informal sources can be affected by externalities. For example, the formal agent may prioritise other competing disease-related groups in their client list, their level of care may be impaired by service coverage or increasing their frequency of contact may reduce their profits. Likewise, informal care may form a conflict with ensuring a household's income or family priorities and the required level of care may also be limited by geographical proximity. These externalities induce a deficit in number of hours available by the care-recipients and form a threshold level in number of hours available at a maximum utility. This threshold is a level of care, after which, providing the required additional hours will be with an anticipated utility loss and as such may produce negative effects for the care provider. Motivation to accept extra hours will require a commitment to mitigate risk to the patient (e.g., an unsupervised individual is at risk of self-harm, actions may result in injuring others, all of which increases demand on already scarce resources). As one (or more) optimality conditions can no longer be satisfied, a second-best equilibrium forms where accepting the deficit hours comes with the anticipatable lower yield of personal welfare (Sen, 1997).

If demand for dementia care is generally inflexible, deficit hours will exert pressure on the system. Either the informal carer must increase their hours beyond their maximum or further formal provisions will be consumed within budgetary restriction. In both situations the system has now become inefficient in terms of overall welfare.

In considering this dynamic of care to the Irish situation, Wimo and Prince (2010) estimate that 60-70 per cent of individuals with dementia in Ireland currently live in the community. Furthermore, Bolin *et al.* (2008) empirically demonstrate that informal care acts as a complement to formal services and can only be a supplement where symptoms are not advanced. The Irish survey presented in this paper finds that the majority of care is informally provided and there is little evidence that formal services are reducing the burden placed on informal care. The current dynamic of care in Ireland is second best and requires regulatory intervention. This study aims to estimate the formal value of dementia-specific care which is provided and indicates how policy intervention could alter the current market equilibrium.

### III DATA AND ANALYSIS

#### 3.1 *Introduction – Alzheimer’s Society of Ireland (ASI) 2007*

In 2007, the Alzheimer’s Society of Ireland<sup>1</sup> developed a questionnaire to assess the dynamics of informal dementia care in Ireland (from here onwards the survey is referred to as ASI, 2007). The questionnaire’s design is drawn from that used in other European countries and has been used to facilitate multi-country comparisons (Alzheimer Europe, 2006). Questionnaires were randomly distributed to carers via Alzheimer’s Society of Ireland service points and carers were asked to complete the survey and return it directly in a pre-paid envelope.

The society is currently the leading community contact point for people with dementia in Ireland and following formal diagnosis, individuals become eligible for membership. In 2007 there were 3,000 members and questionnaires were distributed to a random sample of 720 members. A total of 270 questionnaires were returned giving a response rate of 38 per cent. Initial data was compiled for descriptive analysis in SPSS and was converted into STATA for econometric analysis.

#### 3.2 *Measurement of Informal Inputs to Care*

Carers were asked approximately how many hours per day they spent caring for the person with Alzheimer’s disease/dementia, their answers were categorically indicated over two hour intervals (see Table 1). To approximate the underlying distribution, the median value is taken in each age category forming a continuous dependent variable (Allison and Foster, 2004).

#### 3.3 *Individual Characteristics*

Age is a major factor associated with dementia and the age distribution in this sample is skewed towards the more elderly, with a median range of 75-84 years (see Table 2). Furthermore, caregiver interventions, such as training, help carers to cope with their role and allow them to be more efficient with their time however the ASI 2007 survey finds that only 13 per cent of individuals have been trained to provide care. Access to nursing homes is limited in Ireland and 97 per cent of care recipients live at home or with their carer.

To ascertain the stage of current dementia, respondents were asked what stage their doctor had most recently indicated and responses were either “Early Stage/Mild”, “Middle Stage/Moderate”, “Late Stage/Severe” or “No

<sup>1</sup> Data collection was by MBIMS (market research agency) and received funding from Lundbeck pharmaceutical. The author of this paper sees no conflicts of interest in the data collected and subsequent analysis is independent.

Table 1: *This Table Indicates (from left to right) the Categorical Variable of the Informal “Hours Per Day of Care”, The “Median Value” Used as the Dependent Variable in the Tobit Model, The Sample “Frequency” and Per cent of the Level of Daily Care*

<i>Hours Per Day of Care</i>	<i>Median Value</i>	<i>Frequency</i>	<i>Percentage</i>
Less than 2 Hours	1	13	5
Between 2 and 4 Hours	3	16	6
Between 4 and 6 Hours	5	13	5
Between 6 and 8 Hours	7	14	5
Between 8 and 10 Hours	9	9	3
Between 10 and 12 Hours	11	11	4
Between 12 and 14 Hours	13	13	5
14 Hours or more	14	169	66
Total		258	100

Stage/Severity was Mentioned” (see Table 2). The regression analysis omits “No Stage”<sup>2</sup> and takes it as the reference standard of the other stage related parameters.

A total of 264 respondents indicated their employment status, of which 73 per cent were not working, having either “retired”(43 per cent) or resigned to care (30 per cent). The remainder were either Full-time (13 per cent) or Part-time (14 per cent). The amount of time provided in care for those who were also employed is found to be highly correlated to their proximity to the recipient. This analysis divides the employed group by whether they are cohabiting with the respondent (see Table 2). Those who were not also working showed much less variation in the hours provided (presented later in Table 5), therefore new variables were not constructed for these individuals.

### 3.4 *Functional Limitations and Psychiatric Symptoms*

ASI 2007 assessed symptoms associated with functional impairment asking respondents what their recipient demonstrated at the time of the survey. These responses were categorised into household activities of daily living, general activities of daily living and instrumental activities of daily living (IADL) in accordance with classification guidelines (Roley *et al.*, 2008) and the frequency with which they occurred in the sample is presented in Table 3.

<sup>2</sup> Analysis of the number of symptoms would suggest “no stage/severity was mentioned” has a similar distribution to those with late stage dementia (results available on request).

Table 2: *Summary Statistics of Individual Characteristics Divided into the Demographic Features (Care Recipient's Age, Whether the Caregiver Received Training and Whether the Person with Dementia is Living in a Nursing Home), the Current Diagnosed Stage of Dementia and the Employment/Cohabitation Status of the Informal Carer*

<i>Individual Characteristics</i>	<i>Frequency</i>	<i>Percentage</i>
<i>Demographic Features</i>		
<i>Age of Care Recipient</i>		
45-54 Years	3	1
55-64 Years	15	6
65-74 Years	49	18
75-84 Years	128	48
85 or Over	72	27
Total	267	100
<i>Carer Received Training to Care</i>		
No	228	87
Yes	33	13
Total	261	100
<i>Living in Nursing Home</i>		
No	259	97
Yes	8	3
Total	267	100
<i>Current Diagnosed Stage of Dementia</i>		
Early Stage/Mild	18	7
Middle Stage/Moderate	88	36
Late Stage/Severe	70	28
No Stage/Severity was Mentioned	70	28
Total	246	100
<i>Work Cohabitation Status</i>		
Full-time, Live Together	19	7
Full-time, Live Apart	15	6
Part-time, Live Together	16	6
Part-time, Live Apart	21	8
Retired	114	43
Resigned to Provide Care	79	30
Total	264	100

Psychiatric symptoms commonly cause behavioural disturbances and were assessed. Respondents were asked to indicate which symptoms were problematic and, in a separate question, which symptoms ranked as the most problematic (the relevant symptoms are presented in the lower part of Table 3).



Table 3: *Frequency of Functional Limitations (Symptoms Affecting Activities of Daily Living) and Psychiatric Symptoms (Which Cause Behavioural Problems Which Require Supervision)*

<i>Functional Limitations</i>	<i>Frequency</i>	<i>Percentage</i>
<i>Limitation Performing Household Activities (HDL):</i>		
Cleaning	175	66
Cooking	185	69
Shopping	181	68
<i>Limitations in Activities of Daily Living (ADL):</i>		
Dressing	166	62
Showering/Bath/Wash	204	76
Eating/Drinking	90	34
<i>Limitations in Instrumental Activities of Daily Living (IADL):</i>		
Writing/Reading	176	66
Following Conversation	193	72
Using the Telephone	179	67
Hobbies/Interest	159	60
Group Activities	134	50
<i>Psychiatric Symptoms</i>		
<i>Common Behavioural Symptom:</i>		
Wandering/Restlessness	133	50
Recognising People	166	62
Incontinence	129	48
Inhibition/Poor Self Control	74	28
Concentration/Attention	212	79
Memory/Confusion	234	88
Agitation/Aggression	124	46
Personality Changes/Mood Swings	135	51
<i>Behavioural Symptom (Indicated as Causing Major Concern):</i>		
Personality Changes/Mood Swings	69	26
Wandering/Restlessness	59	22
Recognising People	45	17
Comprehension of Language	36	13

The sample population was representative of regional density and age distribution (Dublin n = 37, Leinster (outside Dublin) n = 84, Munster n = 105, Connaught n = 22 and Ulster n = 22). Carers' ages ranged from under 35 to over 85 years, a median age between and a mean average of 55-65 years. Most

commonly carers were female ( $n = 196$ ) and were equally likely to be caring for a female or male ( $n = 98$  vs.  $n = 96$ , respectively). However, when the carer was male ( $n = 76$ ), they were over six times more likely to be caring for a female ( $n = 66$  vs.  $n = 10$ ).

Survey respondents were most commonly caring for a “Mother or Father” ( $n = 121$ ) or for a “Spouse or Partner” ( $n = 117$ ), with the remaining recipients being “In-Law” ( $n = 11$ ), “Friend” ( $n = 2$ ), or “Other Relative” ( $n = 11$ ) – “Professional Carer” and “Missing” relationships ( $n = 3$ ) were ignored in the analysis. The most common employment status was “retired” (42.7 per cent), however, the remainder were either not working due to “caring role” or “unemployment” (29.59 per cent), or were working “full” or “part” time (27.72 per cent). As would be expected the distribution of the number of hours of care per day is dependent on employment status (Pearson  $\chi^2(28) = 104.2590$ ,  $p < 0.001$ ). Notably, of 71 in paid employment, 46 respondents (64.79 per cent) indicate they had reduced their hours.

### 3.5 Model Specification

The amount of time spent caring ( $y_i$ ) was measured to an upper limit of 14 hours per day ( $y_U$ ) which requires the application of a censored regression model to predict a latent variable ( $y_i^*$ ) informal care time. Such top coding of the hours per day spent caring (i.e., censored above 14 hours) necessitated a censored regression Tobit model (Tobin, 1958). The original application of Tobit model was used to describe non-negative dependent variables, however, a variation of the Tobit (Amemiya, 1985) applies the top censoring limit ( $y_U$ ) according to Equation (1).

$$y_i = \begin{cases} y_i^* & \text{if } y_i^* < y_U \\ y_U & \text{if } y_i^* \geq y_U \end{cases} \quad (1)$$

In this model the latent variable  $y_i^*$  above  $y_U$  cannot be observed while the matrix of independent variable ( $x_i$ ) can be fully observed. Maximum likelihood estimation is shown to be valid and consistent to estimate such Tobit models (Wendelin, 2005) and allows the prediction of hours of informal care including those over 14 hours based on explanatory variables. To ensure comparable representation of early, mid and late stage dementia, inverse probability weighting is applied to the regression (Wooldridge, 2002). The significance of groups of regressors is examined using Wald test (Wald, 1943) and the influence of the overall specification is assessed using a link test (Pregibon, 1980).

The following empirical specification is applied:

$$\hat{y}_i = (\text{Demographics, Stage, Employment; HDL, ADL, IADL; Behaviour Problems}) \quad (2)$$

*Individual characteristics* are captured in *demographic features*, *stage of disease* and *employment status*. *Functional limitations* are accounted for by activities of daily living in the household (*HDL*; such as cooking, cleaning), general (*ADL*; such as dressing, eating), and instrumental activities (*IADL*; more complex tasks such as using the telephone, socialising). Dementia symptoms may also necessitate supervision where individuals have *behavioural problems*. In contrast to *individual characteristics*, Netten and Davies (1990) suggest that *functional* and *behavioural* problems are better regarded as commodities consumed to maintain the individual in the community.

Formal services were also included into earlier model specification but were found to have no effect on the amount of informal care. The assessment of the influence of formal care assessed two additional categories of variables of service use; namely *formal service use* (relating to GP or hospital access) and *community services use* (indicating use of day care, home care and respite). Using Wald test of model significance, both categories had no significant influence; *formal service use*,  $p = .4763$  and *community services use*,  $p = .7358$ .<sup>3</sup> This confirms the complementary nature of informal care and suggests that formal services do not actively supplement informal care time.

#### IV RESULTS

The estimation specification is based on *individual characteristics* (*demographic, employment status and current stage of dementia*), *functional limitations* (*HDL, ADL, and IADL*) and *behavioural problems*. Next, the results of the post estimation test of the model are presented before making specific inferences from the regression.

Overall the model specification was significant ( $p < 0.0001$ ), had a McFadden Pseudo- $R^2$  of 0.2126 and a Link test (Pregibon, 1980) found the model correctly specified ( $P[g(\mu) = \mu] = 0.018$ ) and ( $P[g(\mu)^2 = \mu] = 0.172$ ). These tests conclude that the model is highly significant in explaining informal care time, captures 21.26 per cent of the variance and that the conditional mean is correctly specified in the regressors. Regression output is presented in Table 4.

<sup>3</sup> For further information on these test, please contact the author.

Table 4: *Regression Outputs of the Tobit Model Estimating Daily Number of Hours Spent on Informal Care*

<i>Variable</i>	<i>Coefficient</i>	<i>(Std Err.)</i>
Equation 1: Informal Care Time		
<i>Demographics:</i>		
Age of Care Recipient	1.151†	(0.606)
Recipient Lives in a Nursing Home	-6.619†	(3.433)
Carer Received Training to Care	-2.971†	(1.563)
<i>Current Stage of Dementia:</i>		
Current: Early Stage	-3.886†	(2.205)
Current: Mid Stage	-0.687	(1.174)
Current: Late Stage	2.709†	(1.563)
<i>Employment/Cohabitation Status:</i>		
Full-time, Live Together	4.506	(3.948)
Full-time, Live Apart	-2.710	(3.782)
Part-time, Live Together	9.789*	(4.366)
Part-time, Live Apart	0.736	(3.779)
Retired	8.882*	(3.516)
Resigned to Care	11.646**	(3.660)
<i>Problems with Household Activities of Daily Living:</i>		
Cleaning	1.780	(1.556)
Cooking	-5.015**	(1.848)
Shopping	0.452	(2.002)
<i>Problems with Activities of Daily Living:</i>		
Dressing	3.449*	(1.385)
Bathing	-0.610	(1.494)
Eating	1.412	(1.326)
<i>Problems with Instrumental Activities of Daily Living:</i>		
Read/Write	2.200	(1.430)
Following Conversations	1.156	(1.549)
Telephone Use	-2.615*	(1.237)
Hobbies/Interests	0.507	(1.363)
Socialising	0.308	(1.545)
<i>Behavioural Problems:</i>		
° Language	-2.344	(1.567)
° Aggression	4.285**	(1.428)
° People	-1.375	(1.527)
° Memory/Confusion	-1.198	(1.669)
Wandering	3.449**	(1.334)

Table 4: *Regression Outputs of the Tobit Model estimating Daily Number of Hours Spent on Informal Care (contd.)*

<i>Variable</i>	<i>Coefficient</i>	<i>(Std Err.)</i>
Recognising People	1.332	(1.440)
Incontinence	-0.333	(1.126)
Inhibition	4.065**	(1.477)
Concentration	1.917	(1.664)
Memory/Confusion	-4.299†	(2.269)
Aggression	-3.142†	(1.623)
Mood Swings	-1.483	(1.487)
<i>Intercept</i>	-8.788	(6.874)
Equation 2: Sigma		
Intercept	5.593**	(0.455)
N	240	
Log-likelihood	-1144.947	
F <sub>(35,205)</sub>	9.479**	

Significance level: †: 10% \*: 5% \*\*: 1% [Symbol (°) indicates top ranking problems to the carer.]

The Wald test of the three grouped categories of variables examines their joint significance in estimating informal hours of care. All *individual characteristics* are significant; *demographics features*,  $p = 0.0041$ ; *stage of dementia*,  $p = 0.0402$ ; and *employment/cohabitation status*,  $p < 0.0001$ ). The effects of *functional limitations*, *HDL* ( $p = 0.0196$ ) and *ADL* ( $p = 0.0133$ ) are significant but limitations often associated with earlier stage dementia such as *IADLs* lack significance ( $p = 0.1307$ ). *Behavioural problems* are significant at the 0.05 level ( $p = 0.0264$ ). Age and gender of the care-giver were tested in previous specifications but were found not to be significant predictors ( $p = 0.5456$ ) and, therefore, are omitted in the final model.

In the next section indicators within category are examined and the marginal effects associated with variables are presented to make specific inference on the level of care required.

#### 4.1 *Individual Characteristics*

Informal care steadily increases as *age* rises; this can be associated with age-related progression of dementia or alternatively the rising likelihood of other co-morbidities. Carers who receive formal *training* to care will provide an average of 3 hours less care per day indicating that training is important to ensure sustainability of this relationship. Eight respondents indicated that

their recipient lived in a *nursing home* and were predicted to provide 5 hours less care per day than the average.

As would be expected, coefficients of *dementia stage* variables indicate that demand for care increases with disease progression and show the importance of stage-related weighting in the regression. Later in this section, the dementia stages are revisited to estimate average daily hours of informal care at each stage and associate the proxy-good values. In earlier specifications *Living Together* (dummy variable indicating cohabitation) is found to be highly significant and to have a driving magnitude. To fully capture this effect, the model required an enrichment of *employment status* parameters to also indicate *cohabitations*. This suggests that, on average, carers also living apart from the care recipient provide between 2 to 10 hours less care per day indicating competing priorities. Similarly, *employment status* will influence the time available for care and is found to be the third competing priority for the caregivers' time. Table 5 describes the carer's employment status and whether cohabitating with their recipient influences the hours of care per day that are provided.

Table 5: *The Average Daily Hours of Informal Care and Standard Deviation (in brackets) Dependent on Cohabitation and Employment Status*

<i>Live Apart</i>	<i>Daily Informal Care by Employment Status</i>			
	<i>Full-time</i>	<i>Part-time</i>	<i>Retired</i>	<i>Resigned</i>
Yes	3.76 (2.54)	6.38 (3.46)	13.56 (3.21)	17.48 (4.17)
No	12.76 (4.64)	17.85 (4.37)	17.13 (3.82)	19.41 (3.56)
Total Hours	8.67 (5.91)	11.34 (6.91)	16.77 (3.90)	19.14 (3.68)

Individuals living apart and working full- or part-time provide an average of 10 hours less care per day. Full-time employed carers who are living apart from their recipient will provide an average of 3.76 hours per day and exhibit little relative flexibility to alter their level of care (S.D 2.54). This implies individuals continuing to work while also caring will experience conflicting priorities competing for their time. This raises the research question of how carers' transition from one employment status to another (e.g., full-time to part-time or part-time to resigning to care). This survey does not offer the ability to follow the individuals over time, however, this cross-section does ask how caring affects their work. The survey finds that 50 per cent reduce their hours of work, 35 per cent had resigned to care, leaving only 15 per cent managing to continue working the same hours.

Carers who *resign* to care are significantly more likely to provide more informal care ( $p = 0.008$ ), which may indicate the motivation behind resignation to care. Results find 85 per cent of carers who resign will live with the person with dementia and will provide an average of 9 hours more care per day than those who continue working. Carers who are *retired* from work provide an average of 17 hours of care per day and living apart from the recipient only marginally changes this (reduces to 13 hours). These retired carers are most commonly aged between 65-74 years (40 per cent) and 75-84 years (33 per cent), suggesting their ability may in itself be limited by their own health status. Future analysis should assess transition probabilities from various employment statuses, the relationship to the concept of deficit hours of care and eliciting replacement services (discussed further in the Conclusions section).

#### 4.2 *Functional Limitations*

The significance of *functional limitations* indicates the individuals' need for care and support regularly for activities necessary within daily life. Problems are captured in three forms of activities of daily living; HDLs, ADLs and IADLs. The coefficients in the regression capture the influence of stated problems with each on the required level of informal care. The first set of limitations examined includes *household activities of daily living (HDL)* and are found to occur in approximately 70 per cent of respondents. HDLs are more commonly reported where the care recipient was female, potentially indicating a deficit in domestic maintenance as a result of a role replacement. Regression coefficients indicate that *Cooking* is significantly correlated with less informal care, reducing the level of care substantially. HDL parameters capture a loss in household activities and reflect the carer substituting the recipient in general household duties. Applying the proxy-good values by stage indicates that informal care time for HDLs decrease as dementia progresses (whilst assistance with ADLs is increasing), suggesting that the carer may prioritise more severe symptom care over the basic household duties (shown later in Table 7).

The second part examined under functional limitations is instrumental activities of daily living (*IADL*). This domain of functional activity is associated with higher cognitive ability such as socialising, communication and complex activities. As such decline in this set tends to be primarily associated with earlier stage dementia (Skurla *et al.*, 1988). The lack of significance of this overall group may be associated to the lower sample number in earlier stages and individuals only starting to lose coping skills. The only problem of significance is *telephone use* but with a negative sign this would be correlated with a situation where less care is provided. Two

conclusions are possible: either this indicates a situation where less care is required, given lower level impairment in earlier stage dementia. Alternatively, the association to telephone use may indicate a situation where carers are unable to provide more care (e.g., where working or living far away) and the problem relates to a direct concern whereby the caregiver is reliant on communication to alert them of need. On analysis, concerns related to telephone use are found to become significant in mid-stage dementia, at which stage cohabitation is observed to increase compared to that in early stage dementia. This leads to the feasible conclusion that the breakdown in communication makes the informal carer explicitly aware that the level of care required may be in deficit and may increase the likelihood to cohabitations.

The final components are the *activities of daily living (ADL)* which become a more significant problem from mid-stage dementia onwards. For example, individual's limitations to dress themselves rises as the dementia progresses (early stage 50 per cent, mid-stage 59 per cent and 80 per cent in late stage) suggesting physical disability associated with the latter stage. The regression parameters only find dressing as significant. In Table 3, facilitating personal hygiene (problems with showers, baths, etc.) is found to occur in 76 per cent of the sample and, therefore, may form more of a constant dementia care effect. If the level of care is examined where there is at least one ADL limitation, then there will be an average of 2.5 more hours of care per day. Overall, predicted levels of informal care are significantly explained by activities of daily living and are important in predicting demand by stage.

#### 4.3 *Behavioural Problems*

Behavioural problems are significant predictors of informal care caused by psychiatric symptoms of dementia. *Aggression*, *wandering* and *inhibition* are specific psychiatric symptoms of dementia, each significantly increasing the demand for informal care ( $p = 0.003$ ,  $p = 0.010$  and  $p = 0.006$  respectively). Aggression is found to affect 46 per cent of people and commonly indicates that depressive symptoms may underlie the dementia (Lyketsos *et al.*, 1999). Individuals indicating that their recipient experiences wandering will provide on average 5.2 hours more care per day and this has also previously been identified as an exacerbated effect of depression in dementia. Individuals with dementia may lose their inhibitions which may lead to undesirable behaviour and carers are found to provide approximately 2 hours more care per day for these individuals, predominantly for those with mid-stage dementia.

#### 4.4 *The Estimated Market Value of Informal Care*

Individual characteristics, functional limitations and behavioural problems form the basis of demand for care. The volume of informal care is



strongly correlated to the carer's work life which may conflict with maintaining their own household or productivity. Table 6 presents the average, minimum and maximum hours provided in informal care in early, mid and late stages of dementia. In line with national costing framework for economic evaluations (HIQA, 2010), a general replacement value to the Irish health system is applied. Based on the assumption that a "care assistant (intellectual disability agencies)" would be the generic formal alternative to the informal carer, the annual midpoint salary is taken as €31,942<sup>4</sup> equating to a total staff cost at €33.62 per hour.<sup>5</sup>

Table 6: *By Dementia Stage, The Estimated Average Hours of Informal Care (left) and the Overall Per Diem Replacement Costs Based on a Single Proxy (Care Assistant – Intellectual Disability Agencies)*

Variable	Informal Care (Hours/Day)			Replacement Cost (Euro)	
	Mean	Min.	Max.	Per Diem	95% Conf. Inter.
Early Stage	8.327	1.97	14.721	279.97	212.82 – 347.12
Mid Stage	14.066	1.57	23.027	472.92	430.65 – 515.18
Late Stage	19.274	1.396	23.784	648.00	611.92 – 684.09

These results illustrate that dementia care in Ireland places substantial demand on the informal sector. Early stage dementia will on average consume the equivalent of a full-time working day of care and this level of care more than doubles by latter stages. The range of times provided by stage varies substantially and (as shown in Table 5) lower range is often caused by conflicting priorities related to cohabitation and employment status. Comparing the patterns of informal care by stage, distributions are found to become increasingly skewed with disease progression (kurtosis in early:  $-0.0311$ ; mid:  $-0.4652$ ; and late stage:  $-2.2078$ ). From the progressive volumes of care required, meeting demand may necessitate resignation from work and potentially forming a cohabitation arrangement with the care recipient. Ultimately, the distribution of informal care for late stage dementia is right skewed around a median of 20.43 hours per day, a kurtosis of 8.303 indicating a high density around the median and 95 per cent of carers provide more than 10 hours per day. These results suggest that an absence of sufficient planned formal services place a growing burden on informal carers.

<sup>4</sup> Department of Health and Children. Pay-scales for public sector staff, 2010.

<sup>5</sup> "Care assistant" (intellectual disability agencies) is a modest cost and international informal care cost estimates (Koopmanschap *et al.*, 2008) indicate "community psychiatric nurse" as the appropriate agent for behavioural problems. This would raise the total hourly staff costs to €52.08 which will be revisited later in the application of specific proxy-goods.

The first valuation is a full replacement cost to household outputs given by the average informal carer in Ireland. The primary aim of this full valuation is to highlight the financial risk associated with carer burnout and the associated formal cost of losing all household outputs of that individual. Whilst the full duty of care is unlikely to be accepted by the State, previous research shows that consistent over-burdening of informal carers will result in carer burnout (Angermeyer *et al.*, 2006, Cuijpers and Stam, 2000, Yilmaz *et al.*, 2009). Assuming that a “care assistant” would be the most likely single proxy for an informal carer in burnout, this would value all the total stated outputs per day ranging from €279.97 in early stage to €648 in later stage dementia. The financial impact associable to burnout is best highlighted by the marginal effect of losing one carer; the annual cost of replacing the total household outputs provided for one informal carer would range from €66,681 in early stage to €154,872 per annum at late stage.

Accepting this financial risk associated with caregiver burnout is therefore unlikely, both from within the public finance budget or via a personal out-of-pocket payment. The valuation with respect to carer burnout or loss provide a value weight of the informal carer’s time to offset against any increases in resource allocation to avoid carer burnout (e.g. carer interventions). Whilst an increase in the budget allocated for dementia care in Ireland is merited, spending is likely to continue to fall short of the required level (Comas-Herrera *et al.*, 2010). To make best use of the limited resources, efficient allocation within an assumed dementia budget will be required to achieve the greatest welfare of all concerned. In line with this notion of increasing technical efficiency, the proxy-good values for dementia specific symptoms are estimated to indicate components of care which may, and potentially should, be substituted by formal services.

The associated costs of a “care assistant” is appropriate for replacing the competency of the informal carer for *functional limitations* (*HDL, ADL, IADL*), while a trained “community psychiatric nurse” as a minimal competency level for *behavioural problems*. In this estimation of the informal cost of dementia care, these tasks are assumed to be divided between appropriate agents, applying cost estimation by proxy-good methods (Koopmanschap *et al.*, 2008). Table 7 presents the hours per day devoted to the three functional limitations and behavioural problems to which proxy-good value are applied by stage.

A proxy value for each task is applied; for *behavioural*<sup>6</sup> problems, “community psychiatric nurse” (€52.08); for deficit in HDL, the hourly cost of

<sup>6</sup> Informal care related to *behavioural* problems assumes that care will be for one of the three significant behavioural problems at any one time. So, the mean time spent on either wandering, lack of inhibition or aggression is calculated.

Table 7: *Estimated Hours Per Day Spent on Specific Tasks Forming Multiple Proxy-Goods for Valuation (e.g. HDL, ADL, IADL and Behavioural Problems). “Stage Baseline” is a Constant Level of Dementia Care Independent of the Specific Symptom Related Tasks. The Subtotal is Therefore All Time Specific to Dementia and the Difference is the Household Time for Duties not Related to Dementia*

Dementia Stage	Stage Baseline	Proxy-Goods				Sub-total	Difference (€)	Total
		HDL	ADL	IADL	Behav.			
Early	0.84	-0.51	1.64	0.46	2.43	4.86	3.47	8.33
Mid	1.96	-1.00	2.58	0.80	3.55	7.89	6.18	14.07
Late	3.93	-1.67	3.42	1.15	4.48	11.31	7.96	19.27
Overall	2.51	-1.19	2.81	0.90	3.80	8.83	6.79	15.62

an “HSE domestic” (€30.51); and to stage-specific constants, ADLs and IADLs, the cost of “care-assistant (intellectual disability agencies)” (€33.62) is applied. The difference (diff.) is associated to a distribution held in the error term which will correlate with general household output that is not associated with dementia but, which changes at progressive stages<sup>7</sup>. Equation (3) formally represents this calculation.

$$\hat{y}_{is} = \alpha_s + x_{is}B_k + \varepsilon_{is} \tag{3}$$

In this equation is the level of informal care for individual at dementia stage  $s$ ,  $\alpha_s$  is the stage related constant output,  $x_{is}B_k$  is the matrix of stage specific outputs ( $s$ ) for individual( $i$ ) which the symptom specific coefficient ( $\beta$ ) for the  $k^{\text{th}}$  dementia symptom. The error term ( $\varepsilon_{is}$ ) capture the stage related distribution of regular output in the household which are not associated with dementia care.

Applying the shadow prices to the HSE cited above to each dementia symptom and excluding non-dementia household duties ( $\varepsilon_{is}$ ) provides the stage specific proxy-good values ranging from €240.96 in early stage, €394.92 in mid stage and €570.04 in late stage. While these estimates do not consider preference and utility gain, applying the proxy-good approximates a competency level at where informal carers would be indifferent to accepting formal services over maintaining their duties. These estimated costs are concurrent with observations by the World Health Organisation (Saxena *et al.*, 2007) which find a growing gap between burden of disease and budget

<sup>7</sup> This increase with severity may be explained by two features; firstly shift in shared responsibility to perform household activities by stage and secondly, increase in age care will slow their rate of work.

allocation. In Ireland, a “growing gap” in dementia care results from an absence of statutory policy for older people which will only start to be remedied once appropriate legislation ensures community care services are made available (Cahill, 2010).

#### 4.5 *Study Limitations*

Selection bias may be present in the sample of people with dementia. To assess potential selection bias, the age ranges are found to be representative of the general dementia population. As the comparator, the age distribution of the subpopulation of respondents with dementia in the SHARE survey (Börsch-Supan *et al.*, 2005) is used. Statistical comparison provides a Pearson Chi2 (3) statistic of 2.083 with a p-value of 0.5554. This suggests that the age profile in the ASI, 2007 sample is not significantly different from SHARE<sup>8</sup> and provides confidence that the sample is indeed a random selection of people with dementia.

The relationship of the carer to the recipient may be associated to self-selection. Whether self-selection is present was tested by comparing respondents representativeness of those generally registered with the ASI. The survey observed versus expected demographics are compared to the ASI registry, specifically looking across four categories of the relationships to the recipient (e.g., wife, husband, son, and daughter). Pearson (3) is 5.263 giving a p value of 0.1535, indicating no significant difference in respondent type to member registered on the ASI database.

The random sample of carers being surveyed in relation to carer burden may not accurately represent dementia stage. In the sample, 171 indicated a current stage of dementia which finds 10.06 per cent in early stage, 50.84 per cent mid-stage and 39.11 per cent with late stage. However, the respondents were also asked the stage at the time of diagnosis, this finds: 49 per cent in early-stage, 32 per cent at mid-stage, 2 per cent in late stage and 15 per cent state that no stage was mentioned. From these statistics several points can be concluded. Firstly, less than half of all surveyed were diagnosed during early stage dementia – a fact previously referenced in Irish dementia research (Cahill *et al.*, 2006). Secondly, late-stage censoring may have caused survey non-participation given a lack of time where the level of care required increases (Dura and Kiecolt-Glaser, 1990). Finally, heterogeneity in the carers’ ability to cope and also feelings of stigma reduces earlier stage involvement. To give greater weight to stages which may be potentially censored, an inverse probability weight for the reported stage in the Tobit regression was included.

<sup>8</sup> Comparison available on request.

Ideally, future surveys may account for this, collecting data at the time of diagnosis and repeating data collection to allow for panel analysis.

## V CONCLUSION

Maintaining a person with dementia in the community can offset the cost of long-term care but is concomitant with a growing gap in the ratio “budget allocations to burden of disease” (Saxena *et al.*, 2007). This study shows that dementia care in the Irish community requires a substantial commitment from the informal sector and burden conflicts with the carers’ personal priorities. The proposed theoretical framework is to suggest that increasing demand placed on informal care may only reasonably be sustained until the carer’s individual welfare starts to diminish. Informal care is found to have a direct impact on the carer’s productivity with only 15 per cent managing to continue working the same hours and the remainder either reducing their hours worked or resigning to care. Such levels of care combined with stress associated with functional or behavioural problems as well as reduced income will inevitably lead to emotional exhaustion and ultimately burnout (Yilmaz *et al.*, 2009). In this situation, the full replacement cost would be realised under formal expenditure.

Ireland was predicted to have 42,441 people living with dementia in 2011 (O’Shea, 2004), which represents 1 in 110 people being affected, all of whom will become completely dependent on care-givers by late stage dementia (Kurz, 1999). The proxy-good method provides values to dementia specific output of care by stage; this calculates the cost as ranging from €240.96 (early-stage) to €570.04 (late-stage).

The full replacement cost weight indicates the hypothetical financial risk associated with overburdening carers and burnout; to replace the outputs of one informal carer, the total cost would range from €66,681–€154,872 per annum dependent on dementia stage. The financial risk associable with carer burnout can be minimised by targeting interventions on the carers. Pinquant and Sörensen (2006) systematically review interventions for carers and conclude that combinations of training, respite services and regular counselling can reduce burden, increase welfare and reduce the risk of institutionalisation. Furthermore, such interventions are found to be cost-effective by Gaugler *et al.* (2003) by reducing negative health impacts associated with informal carer and Donaldson and Gregson (1989) through savings accrued in reduced long-term bed use.

The World Health Organisation indicates that resources for dementia be primarily directed to support the informal sector (WHO, 2008). Ireland spends

half the OECD average on dementia care and this valuation calls into question assumptions of costs offset through informal care (i.e. the reduction in direct costs as a result of additional informal care). This indicates that a strategic increase in dementia spend is required to bring Ireland in-line with international standards. It is advised that proxy-good estimates be incorporated into health economic evaluations to ensure efficient resource allocations are socially optimal and to avoid jeopardising the community care network. Future policy planning should ensure that resources are focused towards the core care providers – informal carers.

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