

Appendix - Economic Costs of Dementia

Authors:	Stommel M, Collins CE, Given BA.
Title:	The costs of family contributions to the care of persons with dementia.
Journal details:	The Gerontologist (1994); 34:2, 199-205
Study Aim:	<ul style="list-style-type: none"> To give an account of the costs of family care for dementia patients residing in the community that includes the tangible, yet mostly unpaid contribution of family member. To distinguish care components that are paid for by the family from the costs of families unpaid contributions. To explore factors which predict total costs of family contributions and factors which predict the relative reliance on paid vs unpaid care among families engaged in dementia care.
Study Population	Michigan, United States of America
Eligible population	182 Alzheimers patients and their primary caregiver
Population agreeing to be randomized	Not a randomised trial
Gender distribution	Patients Men - 43 Women - 139
Age distribution	Mean age 73.3 8.4
Degree of cognitive impairment	Moderately severe
Residential setting	Caregiver and patient in some household - 162 Caregiver and patient in different household - 20
Inclusion criteria	<ul style="list-style-type: none"> Patient age over 54 Caregiver report of Alzheimers disease or dementia At least one ADL dependency Existence of a primary family caregiver
Exclusion criteria	Determined by inclusion criteria
Extent to which study population can be extrapolated	There will be differences in the costs of services between states and countries however the principles of determining costs can be extrapolated
Study Design/Type:	Not a randomised trial but one that seeks to determine caregiver costs
Baseline measures	<ul style="list-style-type: none"> Patient household income Caregiver age Patient age Months since diagnosis Household size Patient's functional status Patient's cognitive status Living arrangement Caregiver relation to patient

Comparison of baseline measures between groups	Not a comparative study			
Intervention	No intervention.			
Type/description	Assessment of costs of care.			
Duration of intervention	Three monthly			
Outcome: Cost and outcome measures	<ul style="list-style-type: none"> • Out-of-pocket expenditures for supplies and out of the home services. • Caregiver labour cost. • Family labour cost. • Other labour cost. • Total cash expenditures. • Patient physical functioning. • Patient cognitive impairment. • Patient household income. 			
Measurement of outcomes				
Total costs	Cost of Care to Families During Three Month Period Prior to Interview			
		Adjusted Mean	Range	% of cost
	Out-of-pocket expenditures for supplier and out of the home services	\$522	\$100-\$7600	14
	Caregiver labour cost	\$2890	\$704-\$8446	59
	Family labour cost	\$1106	\$8-5425	12
	Other labour cost	\$2172	\$8-11,800	15
	Total costs to family	\$3,475	\$100-19,565	100
Total costs (cont'd)	Predictors of total costs to families: Functional disability scores, caregiver income, additional \$10,000 of household income. Separate living arrangements.			
Analysis bias	Use of a state-wide average wage rate disregards local variations and thus lowers the reliability of the cost variable. An average cost based on caregiver hourly wage rates was used to estimate the value of services rendered by family members - this may well under-estimate opportunity costs			

(Stommel)

Summary Assessment:	
Level of evidence	Moderate
Recommendations:	Further data, particularly local New Zealand data, is urgently required about the costs to families in caring for those with dementias.
Comments:	Family costs are substantial and should be included in calculations of the total economic costs of senile dementia. Families tend to substitute services paid for in cash for their own labour contributions. Economic status seems to raise the opportunity costs of unpaid family care, separate living arrangements may necessitate greater investment in paid care.

(Rice)

Authors:	Rice DP, Fox PJ, Max W et al.
Title:	The Economic Burden of Alzheimer's Disease Care.
Journal details:	Health Affairs (Summer 1993) 164-176.
Study Aim:	To determine the total formal and informal costs attributable to Alzheimer's disease for persons living in the community and in institutions.
Study Group	A sample drawn from five counties in Northern California - 93 non-institutionalised patients and 94 institutionalised patients together with caregivers and staff. The groups were not comparable as those in institutions were older (39% vs 14% 85 and over), female (77% vs 59%), widowed (59% vs 36%) and with low incomes (38% vs 25%), incomes less than \$US10,000 pa.
Degree of cognitive impairment	Community dwellers - 55% severe dementia Institution dwellers - 94% severe dementia
Extent to which study population can be extrapolated	Small geographic study area means that cost findings are not easily generalised as costs may well vary from state to state and country to country.
Study Design/Type:	No randomisation
Level of randomisation	
Cost measures	When formal and informal costs are combined, annual costs of caring for a person with Alzheimer's disease in the two settings are not significantly different - \$US47,083 for those in the community and \$US47,591 for those in institutions. However for those in institutions, informal services comprise 12% of the total costs of care compared with 73% for patients residing in the community. However for the severely demented in the community the total cost of care was \$US52,667 9% higher than in institutions.
Study strengths	<ul style="list-style-type: none"> • A reasonably large sample • Costs estimated over an extended period • Attempts made to calculate costs associated with medical care, lost productivity and informal care
Study weaknesses	<ul style="list-style-type: none"> • Sample was not random • Limited geographical area • Characteristics of the two groups were dissimilar - probably reflecting

	<p>factors that determine a move to institutional care</p> <ul style="list-style-type: none"> • In Northern California, patients may be diagnosed earlier because of the availability of state funded Alzheimer's disease diagnostic and treatment centres
<p>Summary Assessment: Effectiveness (potential benefit)</p>	<p>For patients with Alzheimer's disease living in Northern California the total annual cost of care is approximately \$US47,000 whether the patient is at home or in a nursing home. For community resident patients, three-quarters of the total cost represents an imputed value for unpaid informal care compared with 12% for those in institutions. Over 60% of the services provided to patients in either care setting were paid out of pocket. With the projected increases in the number of persons at risk of developing Alzheimer's disease, the economic impact of the disease will be significant.</p>
<p>Level of evidence</p>	<p>Grade 4 evidence</p>
<p>Recommendations:</p>	<p>This study carefully assesses the costs of care for Alzheimer's patients in the community and institutions and considers factors such as out of pocket expenses and lost income.</p>
<p>Comments:</p>	<p>There is an urgent need for New Zealand based studies on the costs of care in dementia and of evaluating interventions that might reduce care costs without prejudicing the quality of care.</p>