Modelling costs of dementia in Australia: evidence, gaps, and needs

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Abstract

With the rapid ageing of the Australian population, dementia has emerged as a major health and economic challenge. Consensus exists that the number of people with dementia will grow significantly because the prevalence is strongly correlated with age. However, there are substantial gaps in our understanding of the impacts on the dementia "epidemic" of changes in non-demographic risk factors and of our knowledge of the economic implications. Only a few prevalence-based studies have been conducted to examine the health economics of dementia in Australia. These studies have suggested that considerable resources are absorbed by dementia care, yet there is a lack of integrated models that simultaneously explore epidemiologic and economic perspectives incorporating the impact of preventive and early intervention initiatives. This study reviews the current evidence on the economic implications of dementia in Australia and approaches taken to project the future costs of dementia.

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What is known about the topic?

Dementia has emerged as a leading cause of disease burden in Australia, and the cost of caring for persons with dementia is significant. The incidence and prevalence of dementia will continue to increase because of an ageing population, and estimates suggest that the cost of providing necessary care will rise substantially in the future.

What does this paper add?

This paper reviews available literature and identifies only a small number of studies that attempt to estimate the cost of dementia in Australia. Existing studies provide inadequate evidence as to what targeted policy strategies could be adopted to make care for the rising number of people with dementia cost effective and to manage this emerging health challenge.

What are the implications for practitioners?

Health care providers need to be aware of the increase in demand for services that will result from the predicted increase in the occurrence of dementia. Practitioners need to be cognisant of and implement efficacious and cost-effective strategies that will help prevent dementia or lead to its early detection and intervention.

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POPULATION AGEING has led to an epidemiological shift in disease profile, resulting in age-related illnesses such as dementia becoming major health challenges worldwide. While dementia occurs mainly among older adults, most of whom are already retired from the workforce, this health condition draws considerable resources for treatment and care. In 2005, the number of people with dementia worldwide was estimated at 29.3 million, costing US$315.4 billion in direct medical and non-medical care including informal care; 77% of this cost was incurred in the developed regions where 46% of the dementia sufferers live.[1] Australia is among the countries experiencing a significant growth in the absolute numbers of those with dementia. It is estimated that there were

over 188 000 Australians with dementia in 2005, and the total cost of providing necessary care, including informal care, was estimated to be over US$44 000 (A$58 000) per demented person.[1]

This paper reviews the current evidence on the economic burden of dementia in Australia, focusing on the economic implications at the population level, as opposed to examining the cost effectiveness of specific treatment (including pharmaceutical treatment options) in the assessment and management of dementia. The findings of the review are expected to provide direction for future research to identify ways of responding effectively to the growing burden of dementia in terms of primary and secondary prevention. In view of the promising applications of computer models in exploring alternative interventions for chronic diseases such as diabetes mellitus,[2] the paper discusses the possibility of developing similar models for dementia in Australia.

Methods

Literature published between 1990 and April 2007 was sourced using Medline (using the PubMed interface) and internet search engines Google and Google Scholar. We used various combinations of the key words "dementia", "cost", "economics", "models", and "Australia". We also searched the websites of Access Economics, Alzheimer's Australia, and the Australian Institute of Health and Welfare (AIHW), each organisation having been involved in undertaking research and contributing to the policy debate on dementia. Further literature was identified through the bibliographic sources presented in those publications. Although our focus is Australia, we reviewed the international studies that provided methodological insights and helped to broaden our understanding of the economics of dementia in this country. Only literature that was published and available in English was reviewed.

Costs of dementia in Australia

Our search revealed that only three studies in the published literature have reported the projected costs of dementia in Australia: a study by Access Economics on economic implications of dementia and potential savings from interventions;[3] a major report by the Australian Institute of Health and Welfare which included analysis of the health expenditure and disease burden associated with dementia in Australia;[4] and an international study that examined the worldwide costs of dementia in which estimates were provided for select countries and regions of the world including Australia and Oceania.[1]

Access Economics published a report in 2003 identifying the high burden associated with dementia in Australia.[3] This report, prepared for Alzheimer's Australia, examined the economic impact of, and solutions to, the growing burden of dementia. The study considered three categories of dementia costs: direct health system costs associated with diagnosis and care; indirect costs arising from lower workforce participation, loss of tax revenue, and family and carer costs, social welfare payments, and modifications and aids; and non-financial costs or burden of the disease. The direct health system costs were estimated by using disease costing methodology adopted from Mathers et al.[5] The study estimated that in 2002 there were about 162 000 people with dementia, accounting for 0.8% of the Australian population. The total cost of dementia in 2002 was estimated at $6.6 billion, consisting of $3.2 billion direct costs, $1.7 billion indirect costs, and $592 million in transfer costs. It was predicted that by 2016, dementia would overtake depression and become the largest single cause of disability burden in Australia. The study anticipated that the cost of dementia may reach 3.3% of the gross domestic product (GDP) by 2051, rising from 0.91% in 2002. The projected cost was based on the conservative assumption of demographic growth only, with no change in the real cost of care per person nor the potential impact of therapeutic or preventative interventions.

In a subsequent report published in 2005, Access Economics updated information on dementia prevalence and incidence by projecting likely increases in dementia, again based solely on demographic changes expected in the Australian

1 Projected expenditure for dementia in Australia, 2003 to 2030–31

	Cost (A$ million)					
Year	Admitted patient	All out-of-hospital medical	Pharmaceutical prescriptions	Residential care	Other care	Total health expenditure
2003	149	20	73	993	135	1369
2005–06	159	21	77	1058	143	1458
2010–11	193	25	94	1317	174	1804
2015–16	238	31	116	1625	214	2224
2020–21	292	38	142	1973	263	2708
2025–26	373	48	179	2524	337	3461
2030–31	473	61	226	3267	427	4454
% increase in 2003–2031*	217%	205%	210%	229%	216%	225%

Source: AIHW 2007[4] * Computed by authors.

population.[6] The 96 per 10 000 prevalence rate of dementia in 2003 was projected to increase by 96% to 188 per 10 000 by 2030; and by 189% to 277 per 10 000 by 2050.[6] These increases are significant in relation to the 40% increase (from 20 to 28 million) in the Australian population projected for the same period, 2004–2050.[7] Access Economics also estimated that by 2050, about 175 000 new cases of dementia will be diagnosed in Australia every year, and a quarter of all persons with dementia will be 85 years or older.[6] However, this study did not provide new cost estimates.[6]

The second major study to model the economic cost of dementia in Australia was undertaken by the AIHW.[4] Commissioned by the Australian Government Department of Health and Ageing, the AIHW undertook a large study to profile dementia sufferers and their carers in Australia and to review the availability and quality of data about dementia. As part of this work, the AIHW examined the use of health and aged care services, and projected to 2030–31 the expenditure on medical, pharmaceutical, hospital and aged care services associated with dementia. Limitations were identified in availability and quality of data in Australia that allowed dementia to be examined in terms of patient and carer characteristics, service utilisation, and costs.

The AIHW estimated the expenditure using the method termed the "multiple conditions cost allocation method". This method recognises that a person may have multiple health conditions and estimates the costs of care associated with dementia irrespective of whether or not dementia is the main condition. Expenditure for dementia in 2003 was estimated at $1.4 billion, and projected to reach $4.5 billion by 2030–31. A 177% increase in the number of dementia cases in Australia between 2003 and 2031 was projected.[4] The study assumed no growth in the age-specific rate of dementia and no change in the intensity with which dementia is treated. As Box 1 shows, total health expenditure is expected to increase by some 225% owing to the ageing of Australia's population alone.

The third study is that by Wimo and colleagues,[1] who provided an international comparison of societal costs of dementia. This study estimated direct medical and non-medical costs and cost of informal care. The cost of informal care was computed for three scenarios: 1.3, 3.7 and 7.4 hours of care per day. The cost estimate was derived by applying country and region-specific GDP per capita. For an estimated 188 599 Australians with dementia in 2005, direct cost was estimated at US$2.54 billion (A$3.33 billion), and the cost of informal care

2 Prevalence and costs of dementia in Australia, various estimates

		Access Economics (2003)[2]	AIHW (2007)[3]	Wimo et al (2007)[1]
Current prevalence	No.	162 300	174 700	188 599
	Year	2002	2003	2005
Projected prevalence	No.	581 000	464 700	na
	Year	2051	2031	
Current cost	$	A$6.6 billion (0.91% of GDP)	A$1.4 billion	US$3.8 to 8.4 billion (A$5.0 to 11.0 billion)*
	Year	2002	2003	2005
Projected cost	$	3.3% of GDP	A$4.5 billion	na
	Year	2051	2031	
Methods		Direct and indirect costs. Extrapolation of current expenditures and costs	Expenditure on health and aged care services. Multiple conditions cost allocation method used to estimate the expenditure associated with dementia	Direct medical and non-medical costs and informal care costs. Duration of informal care assumed to be 1.6 to 7.4 hours/day. Country-specific gross domestic product per capita applied to estimate the cost

* 1 × US$=1.31 × A$. na = not available. GDP = Gross Domestic Product.

estimated to have been between US$1.25 and 5.79 billion (A$1.64 and 7.58 billion). Thus, the study estimated that the total cost of dementia in Australia in 2005 was somewhere between A$5.1 and 11.2 billion. A summary of the results and comparison of the methods of these three studies are provided in Box 2.

Unlike the Access Economics[3] and Wimo et al[1] approach of estimating both direct and indirect costs, the AIHW[4] approach was restricted to costs incurred by the Australian health and aged care system. As with the Access Economics study, the AIHW study identified that residential care constituted the most expensive component of health care expenditure, however, the cost estimates from the two studies were of different magnitude. Access Economics estimated the residential care costs in 2002 to be $2.9 billion (91% of the total $3.2 billion direct health care costs); AIHW estimated that the cost of residential care in 2003 was $993 million (73% of the total $1369 million health and aged care system expenditure).[3,4] The direct costs estimated by Access Economics[3] and Wimo et al[1] are in the same order of just over A$3 billion.

Reducing prevalence and costs by interventions

The projections presented above are based on current dementia prevalence and incidence rates and assume no changes in risk factors and disease occurrence. There is emerging evidence to suggest that dementia may be delayed or prevented to some extent by controlling the modifiable lifestyle and clinical risk factors.[8] A small number of international and Australian studies have examined the implications of reducing the prevalence of Alzheimer's disease and dementia on associated costs.[9-12] Box 3 summarises the findings of selected studies on epidemiological and economic implications of interventions.

Brookmeyer and colleagues were among the first to model the public health implications of the delayed onset of Alzheimer's disease (AD).[9] Using a 1997 base prevalence of 2.32 million cases in the United States which was expected to quadruple to over 8 million over a 50-year period, the authors predicted that a 6-month delay in the onset of AD would result in 380 000 fewer cases over the 50-year period; a delay of 5 years would result in a 4 million reduction in the number of Americans with AD after 50 years.[9]

3 Predicted reductions in prevalence and cost of dementia and Alzheimer's disease by delaying the onset of the disease

Study, setting	Focus of analysis	Base prevalence	Onset delay	Reduction in prevalence (approx. 50 years)	Savings
Brookmeyer et al (1998), United States[9]	Alzheimer's disease	2.2 million	6 months 5 years	380 000 4 million	Not given
Brookmeyer et al (2007), World[13]	Alzheimer's disease	All: 26.55 million Early stage: 14.99 Late stage: 11.56	1 year delay in onset and progression (intervention starts in 2010)	All: 9.19 million Early stage: 0.48 Late stage: 8.71 (40 years)	
Access Economics (2004), Australia[12]	Alzheimer's disease	166 107	5 months 5 years	4.8% (45 years) 48.7% (45 years)	10.3 billion 104.9 billion
Jorm et al (2005), Australia[10]	Dementia	171 950	6 months 5 years	5.6% 43.7%	Not given

Extending the one-state model to a multi-state probabilistic model which distinguished AD into early and late stages, a recent work by Brookmeyer et al predicted a fourfold increase, from 26.6 to 106.2 million, in the number of those with AD between 2006 and 2050, in the absence of any interventions.[13] They evaluated the changes in AD prevalence associated with interventions starting in 2010. They concluded that even a modest delay in onset and progression of AD would result in a significant decline in the prevalence of this disease in the long run. Various scenarios derived from the model suggest that effects of interventions on AD prevalence would depend on the target: AD prevalence would be reduced if the disease onset was delayed or both disease progression and onset were delayed; however, delaying the disease progression without delaying onset would result in a lowered prevalence of late-stage AD but an increased early stage and overall prevalence of AD.

Following the earlier work of Brookmeyer et al,[9] Access Economics predicted significant benefits for the Australian economy by delaying the onset of AD: a 5-month delay, with five per cent reduction in age-specific incidence rates, would result in 4.8% fewer cases of Alzheimer's disease in Australia over the period 2005–2050, whereas a 5-year delay would result in a 48.7% reduction.[12] These reductions translate to a cumulative saving of $1.3 billion by 2020 or $6.6 billion by 2040 for a 5-month delay; or a cumulative saving of $13.5 billion by 2020 and $67.5 billion by 2040 for a 5-year delay in onset of disease.

Modifying the incidence function developed by Brookmeyer et al,[9] Jorm and colleagues examined the likely impact on prevalence of delayed onset of dementia in Australia.[10] This study predicted a 5.6% and 43.7% reduction in prevalence by 2050 by delaying the onset of dementia by 6 months and 5 years, respectively.[10] The implications of the delayed onset of dementia on the Australian economy were not estimated.

Discussion

Australia is facing a major challenge in addressing the significant increases in dementia burden predicted over the next 30 to 50 years. The expected increases in the incidence and prevalence of dementia will mean significant increases in the cost of providing care, the high cost of which has been established internationally.[14-19]

The growing challenge of dementia has started to draw the attention of stakeholders. In 2005, the Federal Government of Australia announced a national initiative "Helping Australians with dementia, and their carers — making dementia a National Health Priority", and the Australian Health Ministers' Conference issued the National Framework for Action on Dementia 2006–2010 calling for a coordinated national approach to

deal with the rising dementia epidemic through a number of actions, including research.[20] The Health Ministers' Conference took particular note of the anticipation that dementia and Parkinson's disease together can contribute to the largest increase in health care expenditure in Australia during the period from 2000–01 to 2030–31.[20]

This prompts the need to identify the most effective policy strategies related to therapeutic and preventative interventions to prioritise the scarce resources available for promoting health and caring for older Australians. Mathematical models suggest that delaying the onset of dementia and reducing the age-specific incidence rates by even as little as 5–10% is likely to lead to significant reductions in the number of those with dementia and associated health care costs.[12] Evidence suggests that modifiable risk factors such as the level of physical and cognitive activity, hypertension, and body weight can be altered to reduce the risk of dementia, or to at least delay the onset of dementia.[8,21] There has been no attempt to examine the cost effectiveness of interventions targeting dementia prevention or risk reduction strategies. Future models should take account of the severity and progression of dementia given that a study modelling the early and late stage Alzheimer's disease suggests that different combinations of onset-delay and progression-delay can result in different prevalence levels.[13] Delaying the progression of AD, without delaying the onset, would contribute to decreased late-stage prevalence but an increased overall prevalence. This can have important implications for care needs and costs. As Access Economics suggested, a delayed institutionalisation of demented persons for care would save government expenditure at the expense of family carers.[3] Given the burden placed on carers, there is a need to strengthen strategies that alleviate psychological and financial stress of the families and support them in their care role.

Further research is required to identify the most cost-effective means of reducing the occurrence of dementia, which will result in noticeable health and economic benefits. The Australian government has identified research as one of the key priorities in relation to dementia.[20] The government's concerns and commitments are reflected in the recent funding schemes such as "Ageing Well, Ageing Productively" and dementia strategic grants administered through the National Health and Medical Research Council and Australian Research Council and recently established Commonwealth-funded Dementia Collaborative Research Centres. These initiatives are expected to inform and promote policy research and economic modelling related to the maintenance of cognitive health and the prevention of dementia.

Policy strategies to deal with the dementia "epidemic" can be informed in a number of ways. The need for longitudinal and population-based data that would enable analyses of resource allocation and cost implications has been identified.[22] Conducting prospective intervention studies is an established approach to test alternative policy models in the field, but these studies require substantial investment in time and resources. Computer-based dynamic microsimulation models are an ideal alternative to these, as the computer simulations provide an opportunity to test a range of policy options in a virtual world in a shorter time frame.

Dynamic microsimulation models provide a means of modelling real-life events by simulating the actors of the individual units that make up the system where the events occur. They are based on large unit record datasets capturing the heterogeneity in the population and complexity of the system and policy structures. Individuals are moved progressively (or "aged") through time and undergo life events based on the transitional probabilities of such events. The advances in computational capability and programming languages of computers have made it possible to develop complex simulation models given that adequate input data are available.

The usefulness of computer modelling in examining epidemiological and economic aspects of chronic diseases has been well demonstrated for a number of chronic diseases such as diabetes mellitus and coronary heart diseases in Australia and internationally.[2,23-26] Computer simulation

models are increasingly used to assist in decision making about preventative strategies. Such models are used to project health transitions and outcomes based on natural disease progression, demographic characteristics, functionality, comorbidity, and altered risk status. These models use a simulated population to model the effects specific policy initiatives have on disease occurrence, outputs and associated health care costs by varying assumptions in population characteristics and behaviours, risk occurrence, or intervention options. This approach enables deriving outcome measures at individual level as well as various higher levels of aggregation.

For example, the UKPDS diabetes model was developed based on the longitudinal data collected from the United Kingdom Prospective Diabetes Study (UKPDS) and estimates life expectancy, quality-adjusted life expectancy, and costs of complications in people with type 2 diabetes.[27] The more complex Archimedes model of diabetes mellitus includes detailed patho-physiological, clinical and health management information and interactions, and has been validated against clinical trials as "representing clinical reality as realistically as possible".[28]

While there may be some uncertainty associated with the results of computer simulation models, such methods provide a valuable tool in predicting outcomes according to varying scenarios.[29] The uncertainty may arise from factors such as sampling error in input survey datasets, representativeness of simulated population, and errors associated with model specifications and parameter values. Concerns with uncertainty can be addressed satisfactorily by specifying levels of uncertainties which are known, by updating the model and parameter values when better quality data become available, and by employing sensitivity analysis. As such, a potential computer model of dementia prevention needs to undertake sensitivity analysis and external validation of results, and generate confidence limits around point estimates.

Our review has identified that the methods of estimating the cost of dementia and evaluating the economic rationale for alternative interventions are in the developmental phase in Australia. Previous studies have assumed age–sex-specific incidence and prevalence rates of dementia continue at the present rates, and have applied these rates to the projected populations. Potential costs are assumed to be proportional to the prevalence of dementia. This approach is simple to implement and easy to interpret but fails to take into account the interactions between dementia risk factors as well as dementia care needs and the potential changes in the other factors such as household composition, health and aged care systems, and changed management practices. Also, there is a lack of detailed analysis in the literature on uncertainty surrounding the epidemiological and economic projections, and on sensitivity of the input factors on the outcome measures. Little is known about how the improvements in certain lifestyle factors and clinical conditions could change the pattern of dementia occurrence and how these changes influence public health and economic outcomes. There is a need to devise detailed models that can address these issues. The contributions of the computer models of other chronic diseases such as diabetes mellitus are promising, and the methods could be adapted to model dementia epidemiology and economics in Australia. For example, a diabetes prevention model developed for the Australian population[2] can be adapted for dementia modelling by substituting the base micro-data with another set of data with variables representing clinical and lifestyle risk factors for dementia, updating the demographic and economic input data, and modifying the regression equations.

Conclusion

Given the significant increase predicted in the dementia burden in Australia, contributions to the National Health Priority of "Ageing Well, Ageing Productively" will require additional in-depth analysis of the economics of dementia. Projections of health and economic burden of dementia based only on demographic profile cannot take into account the risk factors which are modifiable. This paper highlights the limitations in current approaches used to project the cost of dementia and suggests the need to develop

more detailed models in order to efficiently experiment with and evaluate policy options. Computer modelling can provide a virtual world in which alternative strategies can be realistically trialled and evaluated.

The development of sophisticated dynamic health and economic outcome simulation models may require a 3 to 5-year research investment. We suggest that funding of the development of such models should be urgently considered. It is only once these models are completed that the health and economic cost-benefits of different prevention and early intervention strategies can be predicted with greater certainty.

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Competing interests

The authors declare that they have no competing interests.

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