



The Minnesota Economic Model of Dementia: Demonstrating Healthcare Cost Savings with the New York University Caregiver Support Intervention

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Executive Summary

No therapies are known to substantially alter the course of dementia and associated treatment costs. However, enhanced support services for caregivers for people with dementia have been shown to improve caregivers' capabilities and well-being and delay patients' institutionalization.

Using a model that simulated disease progression, place of residence, and costs of care, we estimated the economic impact to Minnesota from offering the New York University Caregiver Intervention (NYUCI), an enhanced support services program for adult caregivers of community-dwelling people with dementia. We estimated the impact of the NYUCI on:

1. the potential healthcare savings to all eligible people in the state, assuming all current and future caregivers participate in the NYUCI from 2010 to 2025;
2. the net healthcare cost savings, inclusive of program costs, to eligible caregivers, assuming three less-than-complete levels of participation in the NYUCI from 2010 to 2025 (5% of all caregivers, 10% and 30%);
3. the potential indirect cost savings to all eligible people in the state, assuming all current and future caregivers participate in the NYUCI from 2010 to 2025.

Results indicate that approximately 5 percent more people with dementia would remain in the community from year 3 (2013) on, and that 19.3 percent fewer people with dementia would die in institutions over fifteen years. During those years, Minnesota could potentially save as much as \$1.24 billion (\$996 million in discounted dollars) in direct healthcare costs. The estimated savings in net healthcare costs during those years, including all program costs except for program marketing, were \$61.8 million, \$103.7 million, and \$250.6 million, assuming 5, 10, and 30% of caregivers participate in the NYUCI, respectively. Estimated potential indirect cost savings are also substantial, well exceeding the estimated direct healthcare cost savings.

These findings suggest that broader access to enhanced caregiver supports is a promising way to moderate the growing economic burden of dementia. Substantial long-term savings are possible even without a breakthrough in the pharmacologic treatment of the disease. These direct healthcare cost savings would benefit taxpayers (through reduced expenditures for the Medicaid program) and people with dementia and their families, who largely pay the medical and facility fees for those in residential care settings. Other payers who would benefit include the Medicare program, commercial health plans and long term care insurers, to the extent that they fund these formal care services. The substantial indirect cost savings with enhanced support services would benefit caregivers and likely their employers through improved quality of life and increased productivity. Enhanced support services programs for dementia caregivers, such as the NYUCI, are cost-effective ways to manage dementia while researchers continue to seek effective treatments for the disease.

Background

ACT on Alzheimer's (ACT) is a voluntary collaborative in Minnesota convened in 2011, with the goal of implementing legislative recommendations to prepare the state for the personal, social and budgetary impacts of dementia. One of ACT on Alzheimer's five leadership groups set out to identify and encourage investment in promising approaches that reduce costs and improve care. The leadership group decided to develop a model useful both now and in the future to provide Minnesota policy makers and health care leaders with relevant estimates of potential cost savings associated with varying dementia care approaches to help guide the investment of resources in the future. To this end, the group engaged healthcare researchers to develop an economic model to estimate the cost-saving potential of proven interventions.

Given multiple and diverse stakeholders, the leadership group sought to estimate the impact of one or more care interventions from varying perspectives, including the state-wide Minnesota societal and health system perspectives as well as from the perspective of the Minnesota Department of Human Services, the state's public payer who serves low-income Minnesotans with dementia. At this time the model has been configured to estimate potential and net cost savings from specific perspectives of interest. The same approaches can be used to estimate results from other perspectives and interventions as well as simulate other economic outcomes (such as return on investment or cost-effectiveness) with structural and parameter changes as appropriate.

This paper describes the development of the model, including the initial choice of intervention and modeling approach, and provides a high-level overview of the study methods and results. Further methodologic details and more detailed results can be found in Long et al. 2014 as well as in forthcoming peer-reviewed publications¹.

Clinical and Economic Burden of Dementia

The burden of dementia is widely documented and increasingly recognized in policy settings. Although estimates of the prevalence of dementia in the United States vary, few doubt that the number of people affected is large and increasing with the aging of the population². One recent estimate yielded a prevalence of 14.7% in people older than 70 years of age, approximately 4.1 million individuals in 2010³. More than 15 million family members provide unpaid care for these individuals, often at their own physical and emotional expense⁴.

Annual dementia-attributable direct costs in this population were estimated at \$109 billion; total cost estimates were \$159 to \$215 billion, depending on how the monetary value of informal caregiving was calculated³. The direct cost of care alone ranks expenditures for dementia similar to expenditures for heart disease and substantially higher than expenditures for cancer. These costs are projected to more than double by 2040³. Additionally, since nursing home costs are a primary driver of dementia-related expenditures, the high rate of institutionalization contributes substantially to state and federal expenditures⁵⁻⁷.

Recognition of this burden led Congress to pass and President Barack Obama to sign the National Alzheimer's Project Act in 2011. The act required the creation of a national strategic

plan to address the escalating crisis of Alzheimer's disease and to coordinate efforts to combat the disease across the federal government⁸. And, even in an era of limited research resources, the National Institutes of Health distributed \$45 million in new funding in 2013 to support innovative studies of Alzheimer's disease⁹. Furthermore, the fiscal year 2014 budget included an increase of \$122 million for Alzheimer's research, education, outreach, and caregiver support¹⁰.

ACT on Alzheimer's Collaborative

In 2009, to tackle the mounting Alzheimer's crisis in Minnesota, the Minnesota Legislature charged the Minnesota Board on Aging to establish the Alzheimer's Disease Working Group (ADWG) and make recommendations for policies and programs that would prepare Minnesota for the future. The ADWG developed a set of recommendations for the Legislature in January 2011. A voluntary coalition, now named ACT on Alzheimer's, was subsequently formed to focus on implementing the recommendations (see <http://www.ACTonALZ.org>). As a statewide collaboration, ACT on Alzheimer's fosters collective ownership and accountability in preparing Minnesota for the clinical and economic impacts of Alzheimer's disease and related dementias. The collaboration has more than 300 participants and 60+ nonprofit, governmental and private organizations.

A goal of ACT on Alzheimer's was to develop a model useful both now and in the future to provide Minnesota policymakers and healthcare leaders with relevant estimates of potential cost savings that could be achieved by investing in evidence-based dementia care interventions. The Minnesota Economic Model of Dementia was developed as a vehicle for influencing care delivery and payment policy to ensure that persons with dementia and their caregivers receive optimal care and support in a manner that both improves their quality of life and is likely to reduce the State's and other payers' burden.

Choice of Intervention

The ACT on Alzheimer's leadership group, focusing on identifying and investing in promising care interventions, convened a number of times to discuss the evidence on interventions that had the potential to moderate the economic burden of dementia. The group considered evidence surrounding early identification of disease, pharmacologic treatments, and models to improve continuity of care for persons with dementia.

Early Identification

Being able to identify dementia earlier in the course of the disease clearly has clinical advantages, including improved coordination and continuity of care around dementia progression. Research has demonstrated that early identification alone is possible through screening, although whether this approach has any economic benefits is currently

undetermined due to limited research in this area and the absence of therapies that prevent, cure or significantly delay symptoms¹¹.

Pharmacologic Treatment

Currently there are five therapies approved by the United States Federal Drug Administration for management of Alzheimer's disease. Most of these medications are classified together as cholinesterase inhibitors, which are approved for mild-to-moderate Alzheimer's disease. The additional medication option, memantine, is approved for the treatment of moderate-to-severe disease. While initially these medication options held great promise to delay disease progression, systematic literature reviews have been less favorable and currently the effectiveness of drug treatment remains controversial¹². Even if clinical benefits exist with pharmacologic treatment, they come at substantial cost and it is unlikely that drug treatment is cost-saving or even cost-effective¹³⁻¹⁷. For these reasons access to these medications is currently limited in some countries, given the limited value of drug treatment¹². Following extensive discussion, the ACT on Alzheimer's leadership group decided that the research on pharmacologic treatment is inconclusive regarding clinical effectiveness and the potential for cost savings and it was not chosen to be a focus of economic model simulations at this time.

Improved Continuity of Care

Several types of interventions may be grouped under the concept of improved continuity of care or care coordination. The National Coalition on Care Coordination defines care coordination as "...a client-centered, assessment-based interdisciplinary approach to integrating health care and social support services in which an individual's needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an identified care coordinator following evidence-based standards of care".

An expanding body of literature demonstrates that improved coordination of care practices are effective in ameliorating behavioral and psychological symptoms in persons with dementia and reducing distress in caregivers¹⁸⁻²⁰. Positive results have been observed in multiple controlled and translational studies in clinical and community settings^{18,20}. Formal evaluations have been conducted of several primary-care based coordinated care models for persons with dementia²¹⁻²³. These studies suggest substantial benefits for both caregivers and people with dementia, including improvement in the quality of care and in behavioral and psychological symptoms, without significantly increasing the use of pharmaceutical interventions. A recent study of a primary care based collaborative care model documented nearly \$3,000 in annual savings per patient, largely attributable to reduced rates of hospitalization²⁴. However, the literature to date is limited and conflicting as to whether economic benefits to these models exist, such as reduced emergency room visits, hospitalization, or delayed nursing home admission.

From an economic perspective, a more promising form of improved continuity of care may be the transitional care model that focuses on improving the multiple transfers of persons with chronic conditions between hospitals, nursing homes, and community settings, where evidence has shown that continuity of care often falters²⁵. Naylor and colleagues at the University of Pennsylvania have shown through a randomized controlled trial that a transitional

care model can reduce repeat hospitalizations in a general elderly population²⁶. This model has been studied with favorable results in a dementia population but results are still pending academic publication. Currently the evidence in the literature remains limited regarding cost savings associated with either primary care-based coordinated care models or transitional care models for persons with dementia.

Enhanced Caregiver Supports

Nationally, 44% of community-dwelling persons with dementia live with an adult caregiver, most often a spouse or adult child²⁷. In 2012, an estimated 15 million dementia caregivers provided 17.5 billion hours of unpaid care²⁸. These caregivers provide a wide range of unpaid services, including helping with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and managing behavioral symptoms of the disease. Caregivers frequently provide this care at the expense of their own wellbeing and productivity²⁹⁻³¹. Caregiver stressors in conjunction with care recipient characteristics have been shown to predict nursing home admission³². Institutionalization has multiple consequences, not the least economic, because nursing home costs can greatly exceed the cost of community-based care.

Education and support programs for dementia caregivers have been demonstrated to have multiple benefits. Studied programs have multiple components and may combine individual counseling, family sessions and support, and ongoing assistance to help the caregiver cope with the behavioral symptoms that often accompany the progression of disease. Program benefits include reduced levels of caregiver stress and depression, reduced time spent caregiving, and delayed nursing home placement³³⁻³⁵.

Initial Focus for the Economic Model: The New York University Caregiver Intervention

Based on this review of the evidence regarding possible cost saving interventions, the ACT on Alzheimer's leadership group reasoned that without a clinical breakthrough that can substantially alter the course of disease, the best current evidence-based approach to reducing the costs for persons with dementia may be through provision of enhanced caregiver support. The Minnesota Economic Model of Dementia was initially used to project the healthcare cost savings in Minnesota associated with participation in the New York University Caregiver Intervention (NYUCI), a well-studied enhanced caregiver support program.

The NYUCI was developed in the 1980s to educate caregivers about dementia, involve the family to support the primary caregiver, and provide the caregiver with tools to cope with the behavioral symptoms of the disease. This program consists of two individual and four family counseling sessions, encouragement to participate in weekly support groups, and ongoing ad hoc telephone counseling. Counseling sessions are tailored to meet the needs of the caregiver and family. Previously documented benefits, identified through randomized controlled trials, include improved levels of caregiver wellbeing and capabilities, and an estimated median delay of 557 days before permanent residential placement of the person with dementia³³.

Minnesota Economic Model of Dementia

The Minnesota Economic Model of Dementia is the first formal economic evaluation of the cost savings associated with implementing the NYUCI program. It is a population-based microsimulation Markov model to simulate disease progression and place of residence of Minnesotans with Alzheimer's disease and other related dementias. The model tracks individuals as they move through discrete health states and accumulate costs over 15 years under two scenarios: (1) no enhanced caregiver supportive services, in which adult caregivers of community-dwelling persons with dementia do not receive specialized supportive services in addition to usual care; and (2) enhanced caregiver supportive services, in which adult caregivers participate in the NYUCI. The model is informed by primary data collection as well as the literature on the epidemiology, natural history, costs, and evidence-based management of the disease^{27,33,35-43}. A full discussion of the research methods, model specifications, additional results and limitations can be found in Long et al. 2014 and the accompanying online Appendix¹ (see <http://www.actonalz.org/economic-impact>).

Model Results

Potential Healthcare Cost Savings

The Minnesota Economic Model of Dementia was used first to estimate the maximum potential cost savings associated with the NYUCI, without incorporating variable implementation factors such as program and marketing costs and less-than- complete participation rates. These results appeared in Health Affairs in April, 2014¹. Results suggest that significant direct healthcare savings and other benefits are possible.

- Approximately 5 percent more people with dementia would be able to remain in their homes each year rather than moving to a residential facility, after 3 years of program implementation.
- Approximately 19 percent fewer people with dementia would likely die in institutional settings after 15 years of implementation.
- Minnesota could save as much as \$1.24 billion (\$996 million in discounted dollars) in direct healthcare cost savings over 15 years of program implementation.

These results do not include program and marketing costs. They also assume that all unpaid adult caregivers living at home with the estimated 30,872 Minnesotans with dementia in 2010, and all caregivers of newly diagnosed future cases, were to participate in the NYUCI. While this assumption is unrealistic, these initial results indicated the strong probability that enhanced caregiver support is a promising way to moderate the growing economic burden of dementia. Accordingly, the ACT on Alzheimer's leadership group decided to extend the analysis

to investigate cost savings under three different “real world” participation scenarios as well as account for program costs.

Net direct healthcare cost savings

The Minnesota Economic Model of Dementia was extended to project the likely net cost savings associated with the NYUCI by incorporating estimated program costs and varying participation rates of caregivers of people with dementia in Minnesota. Results suggest that, in addition to allowing more people with dementia to live and die at home, as noted above, net direct healthcare savings are achievable within a few years of program implementation. The following table summarizes the net direct healthcare savings at three possible levels of program participation by caregivers.

	Projected Cumulative Net Direct Healthcare Cost Savings for Minnesota		
	Proportion of 36,786 Eligible Caregivers in 2011		
	Participating in the NYUCI/		
	Initial Number of Caregiver Participants		
	5% / 1,840	10% / 3,678	30% / 11,035
Net Savings:			
After 3 Years	\$ 281,000	\$ 2,500,000	\$ 795,000
After 5 Years	\$ 6,000,000	\$ 17,200,000	\$ 38,300,000
After 10 Years	\$ 33,000,000	\$ 60,800,000	\$ 145,800,000
After 15 Years	\$ 61,800,000	\$ 103,700,000	\$ 250,600,000

These estimated direct healthcare cost savings account for all program costs but do not include costs to increase awareness of the program and encourage participation. These marketing costs could not be credibly incorporated into the model because the approaches to marketing the program have not been determined and may vary substantially based on methods used. However, the estimated net savings suggest broad latitude to conduct outreach and awareness while still providing overall net savings after three or four years of program implementation.

Indirect Costs Associated with Caregiver Burden

The dementia caregiver burden is substantial. As noted earlier, an estimated 15 million caregivers provided 17.5 billion hours of unpaid care nationally in 2012²⁸. The indirect costs associated with this time spent caregiving have been estimated between \$50 to \$106 billion, depending on how the monetary value of informal caregiving was calculated³. The ACT on Alzheimer’s leadership group was interested in determining whether enhanced caregiver support might reduce this economic burden for caregivers, in addition to the direct healthcare savings for patients, families, and payers. The Minnesota Economic Model of Dementia, therefore, was extended to include indirect costs associated with time spent caregiving.

While time spent by caregivers on ADL and IADL related tasks was not measured in the NYUCI, there is evidence from other randomized trials to suggest that caregivers who receive enhanced supports can reduced their time spent caregiving. For example, as observed in the Resources for Enhancing Alzheimer's Caregivers Health (REACH II) randomized trial, caregivers saved, on average, 1.3 hours daily in caregiving tasks with enhanced support³⁵. We quantified this impact in the Minnesota Economic Model of Dementia in order to estimate the potential indirect cost savings for all caregivers of Minnesotans with dementia living in the community. As there currently is no consensus on how to value the economic impact of caregiver burden and the noted impact of method on estimated indirect costs, we varied this valuation approach in alternate analyses³. However, regardless of which approach to valuation is applied, the indirect cost savings to Minnesotans with enhanced caregiver support greatly exceeds the estimated direct healthcare cost savings.

Implications

There are multiple potential beneficiaries of these estimated direct healthcare cost savings. First, taxpayers and people with dementia and their families would potentially benefit as a result of delaying or avoiding placement in residential care settings. Because the Medicaid program and families are the main payers of healthcare costs for people living in residential care settings, delaying placement of people with dementia into these settings reduces these costs substantially.

In addition, to the extent that other payers, including Medicare, commercial health plans and long term care insurers, cover medical and facility fees for people residing permanently in residential care facilities, these payers may benefit financially from their enrollees' longer community residence and reduced use of nursing facilities and assisted living settings. Additionally, we believe the business community would also benefit because employees who are caregivers may be able to stay in the workforce longer, take less time off, and work with less stress as they get needed support with an enhanced caregiver support program.

In summary, these results from the Minnesota Economic Model of Dementia demonstrate that the NYUCI would be a promising way to moderate the growing economic burden of dementia while research continues to find a cure or treatments to delay the progression of the disease. In addition to offering a potential financial benefit to payers and society at large, delayed residential placement will enable more individuals with dementia to spend more time at home as their disease progresses; and even to possibly die at home rather than in a care facility, an end-of-life scenario that many people prefer.

The Consultants Who Developed The Minnesota Economic Model of Dementia



Steven S. Foldes, Ph.D., is a social scientist with more than 30 years of experience conducting public health and health services research and leading research teams. Dr. Foldes has authored many peer-reviewed articles and book chapters. Following a career in applied research that spanned state government, health plans and private industry, in 2011 he started Foldes Consulting, LLC, an independent consulting practice, and was appointed an Adjunct Associate Professor of Epidemiology and Community Health at the University of Minnesota. Dr. Foldes was a Bush Foundation Leadership Fellow. His work has been widely cited in the scientific literature and recognized with the first national Blue Cross and Blue Shield Association “Best of Blue” award for health services research.



Kirsten Hall Long, Ph.D., is a senior health economist and consultant with more than 20 years of applied economic, clinical and outcomes research experience. Her diverse professional career includes academic research positions held in provider, payer and consultative settings, when she gained considerable expertise in measuring the quality and value of health care service delivery from varying perspectives. Dr. Long has substantial peer-reviewed publications and has contributed to and served as co-investigator on federal, foundation and industry funded grants. She is a founding member of health economic and outcomes research organizations and continues to actively serve on review panels, committees and task forces where health economic expertise is needed.

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