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Medicaid Savings From The New York University Caregiver Intervention for Families with Dementia

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Abstract

Purpose of the study: The economic burden of dementia is substantially borne by state Medicaid programs. We estimated savings, from the state payer perspective, from offering the New York University Caregiver Intervention (NYUCI), a well-studied caregiver support and counseling program, to eligible Minnesota Medicaid enrollees.
Design and Methods: A population-based microsimulation Markov model predicted and compared costs over 15 years with and without implementation of the NYUCI for family caregivers of community-based Medicaid eligibles with dementia. The model was informed by primary analysis of Minnesota Department of Human Services (MN DHS) data, and literature on the epidemiology, natural history, costs, and evidence-based management of the disease. Primary outcomes were predicted cumulative total direct costs, including medical, facility, and waiver-program payments for eligibles, and estimated costs of providing the NYUCI.
Results: Approximately 5–6% more eligibles with dementia would remain in the community annually from year 3 (2014) on, so that over 15 years 17% fewer would die in nursing homes (NH) if their caregivers received the NYUCI. After 15 years, MN DHS could realize savings of $40.4 million (2011 dollars, discounted at 3%) if all eligibles/caregivers enrolled. Savings were expected 5 years after implementation. Multiple sensitivity analyses, including best-and worst-case scenarios, estimated results ranging from 15-year cumulative savings of $178.9 million to a cumulative loss of $7.3 million, respectively, driven largely by assumed program effectiveness.
Implications: State payers can use enhanced caregiver support to moderate the growing tax burden of dementia, even without a breakthrough in the pharmacologic treatment of the disease.

Keywords: Cognitive disorders, Alzheimer's disease, Health services research, Costs, Caregiver support

Purpose of the Study

The clinical (Alzheimer's Association, 2016; Brookmeyer et al., 2011; Hebert, Weuve, Scherr, & Evans, 2013) and economic (Alzheimer's Association, 2016; Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Kelley, McGarry, Gorges, & Skinner, 2015) burden of dementia is widely documented and increasingly recognized in policy settings. Although estimates of the prevalence and incidence of dementia in the US vary and have become newly controversial (Langa et al., 2016; Satizabal et al., 2016), few doubt

the number of persons affected is large and increasing with the aging population.

The financial consequences of this demographic reality raise profound public policy challenges. More than two-thirds of Medicaid's budget has historically been spent on the elderly and disabled, and the program is the largest single payer of NH services in the country, financing about one-third of the total spending (Peterson Foundation, 2017). For instance, nearly one of every two dollars spent on long-term care in Minnesota comes from Medicaid (Held, Lewis, Johnson & Johnson, 2016), and at least two-thirds of those long-term care dollars support care for people with Alzheimer's and other dementias (Alzheimer's Association, 2016).

Anticipating the policy challenges accompanying these demographic changes, Minnesota's ACT on Alzheimer's Collaborative was founded in 2011 to prepare the state for the personal, social, and budgetary impacts of dementia. Following a systematic health economic literature review of dementia treatment strategies, the ACT leadership group commissioned an economic model to guide public policy by estimating the cost saving potential of enhanced caregiver support services (ECSS) for family caregivers of community-dwelling Minnesotans with dementia. ECSS are evidence-based community-based models that provide education and supportive services for informal caregivers of people with dementia. The most effective have multiple components, such as individual counseling, family sessions and support, and ongoing ad hoc caregiver assistance. Demonstrated benefits include reduced caregiver stress and depression, reduced time spent caregiving, and delayed residential placement of the person with dementia (Belle et al., 2006; Gaugler, Reese, & Mittelman, 2013; Gitlin et al., 2003; Mittelman, Haley, Clay, & Roth, 2006; Nichols et al., 2008). The group reasoned that without a clinical breakthrough that can substantially alter the course of the disease (Casey, Antimisiaris, & O'Brien, 2010), the best evidence-based approach to reducing the costs for persons with dementia is to enhance support of their family caregivers.

Nationally, 44 percent of community-dwelling people with dementia live with a family caregiver, most often a spouse or adult child (Alzheimer's Association, 2012). These caregivers provide a wide range of services, including helping with activities of daily living, instrumental activities of daily living, and managing behavioral symptoms of the disease. Caregivers frequently provide this care at the expense of their own wellbeing and productivity (Alzheimer's Association, 2013; Alzheimer's Association, 2016; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Mausbach et al., 2010; Schubert et al., 2008). Caregiver stressors in conjunction with care recipient characteristics have been shown to predict NH admission (Gaugler, Yu, Krichbaum, & Wyman, 2009). Institutionalization has multiple consequences, not the least economic, because NH costs can greatly exceed the cost of community-based care.

In fact, this Minnesota economic model suggested potential savings of $996 million in direct care costs over 15 years, if all eligible caregivers participate in ECSS, as implemented in the New York University Caregiver Intervention (NYUCI) (Long, Moriarty, Mittelman, & Foldes, 2014). Although projected savings are substantial, suggesting broader access to ECSS may be economically favorable, the model did not account for ECSS program costs, varying rates of program enrollment by caregivers, and perhaps most importantly for policymakers, did not estimate results by specific payer perspective. Recognizing that NH costs are a key driver of Medicaid expenditures, and the high rate of institutionalization for dementia contributes substantially to Medicaid expenses nationally (Gaugler, Duval, Anderson, & Kane, 2007; Luppa et al., 2010; Yang, Zhang, Lin, Clevenger, & Atherly, 2011), we refined and present here our enhanced economic model, extended to estimate the cost-saving potential to Medicaid of providing ECSS to eligible Minnesotans with dementia, and included intervention costs at different levels of program uptake.

Design and Methods

We developed a population-based microsimulation Markov model to simulate disease progression by place of residence of Minnesota Medicaid enrollees, ages 65–99, with Alzheimer's disease (AD) or other dementias. In this evaluation from the state payer perspective, we replicated the modeling approach and structure employed in our previous study (Long et al., 2014). This extension was informed by primary analysis of Minnesota Department of Human Services (MN DHS) data, and the literature on the epidemiology (Graham et al., 1997; Knopman, Petersen, Cha, Edland & Rocca, 2006; Kokmen, Cha, & Rocca, 1999; Minnesota Department of Administration, 2013), natural history (Neumann et al., 2001), costs (Mittelman, Epstein, Paone, & Walberg, 2010), and evidence-based management of the disease (Mittelman, Haley, Clay, & Roth, 2006).

The model tracked eligibles as they moved annually through three discrete health states (living in the community, living permanently in a NH, and dead) and accumulated costs from 2011 to 2026, based on severity-specific annual transition probabilities between health states. Accumulated costs are compared under two scenarios: with ECSS, in which their spouse or adult child caregivers participated in the NYUCI; and without ECSS. The NYUCI has a strong evidence base built on an 18-year trial, and consists of six sessions of individual and family counseling within 4 months of enrollment, tailored to meet the needs of the primary caregiver and family, recommendation to participate in an ongoing support group, and ad hoc telephone counseling as needed (Mittelman et al., 2006). The program has been validated in additional trials (Gaugler et al., 2013; Mittelman, Brodaty, Wallen, & Burns, 2008), and translated in multiple demonstration projects, including in seven US states and in fourteen Minnesota urban and rural sites (Mittelman et al., 2010).

Target Population—Minnesota Medicaid Program

Many low-income Minnesotans with dementia are served by two public programs, Elderly Waiver (EW) and Alternative Care (AC). EW is a federal Medicaid waiver program for people who receive Medicaid benefits, including medical coverage plus home and community based services. AC is a smaller waiver program (only state-funded until 2014) without healthcare coverage for persons not yet Medicaid eligible.

Both programs' purpose is to promote community living and independence with services designed to address individual needs and choices. These programs fund home and community-based services for people aged 65 years or older who require the level of care provided in a NH but choose community residence. Services vary at the individual level and include long-term care services in the community such as home health and chore support. Residential services such as assisted living are only available in EW.

Prevalence of Dementia in Minnesota Medicaid Enrollees

Measured prevalence of dementia among Medicaid enrollees exceeds that observed in non-Medicaid populations (Gaugler et al., 2007; Luppa et al., 2010). Since eligibility criteria and population characteristics differ by state, we attempted to directly estimate prevalence among Minnesota Medicaid enrollees instead of relying on national estimates.

Identifying MN DHS enrollees with dementia proved difficult since no single data source was comprehensive for persons in both community and residential care settings and also both sensitive and specific. We therefore used ICD-9-CM diagnosis codes and/or Orientation-Memory-Concentration Test results administered during initial eligibility screening. Diagnosis codes to identify dementia were similar to those in observational studies, excluding mild cognitive impairment (McCarten, Anderson, Kuskowski, McPherson, & Borson, 2011). A weighted error score > 9 on the memory test indicated dementia (Katzman et al., 1983). We adjusted prevalence counts for missing scores (typically for persons with limited English skills) based on program-specific prevalence rates among persons with a valid score.

Given transitions between programs, we grouped dementia cases into AC, EW, or NH based on first service use in 2011 claims. Prevalent cases were further restricted to those living with a spouse or adult child caregiver to be consistent with NYUCI trial design. Forty-two percent of AC and 31% of EW enrollees with dementia lived with an eligible caregiver in the community, based on living arrangement information in eligibility files. Finally, we distributed estimated prevalence across disease severity (mild, moderate, and severe) as observed in the Canadian Study of Health and Aging, modified based on expert opinion towards greater severity, due to eligibility rules, among those enrolled in these community programs (Graham et al., 1997).

Incidence of Dementia in Minnesota Medicaid Enrollees

As a population-based model, incident cases were added annually to prevalent cases. Lacking data on date of dementia diagnosis, we were unable to directly estimate annual incidence. Instead, we calculated the age- and gender-specific ratio of published incident-to-prevalent cases derived from rates observed in Rochester, Minnesota (Knopman et al., 2006; Kokmen et al., 1999). We applied this ratio to our prevalence of dementia among eligibles to estimate age, gender, and program-specific incidence rates. These incidence rates were applied to expected trends in program populations to predict counts of incident cases from 2011 to 2026. Program-specific population trends were driven by expected state demographic changes (Minnesota Department of Administration, 2013) and assumed constant eligibility rules. Counts were subdivided by living arrangement and stratified by disease severity as described for prevalent cases. Table 1 presents estimated severity-specific counts of prevalent and incident AC and EW enrollees with dementia living in the community with an informal caregiver. The model assumes age-specific incidence rates remain constant over time; the rise in incident cases reflects projected increasing numbers of older adults in the population (Rocca et al., 2011).

Table 1. Estimated prevalence of Minnesota Medicaid enrollees with dementia living in the community with a spouse or adult child caregiver who were eligible for the NYUCI, 2011, and incidence of dementia in selected years, 2012–2026

	Base-case value
Prevalence of Medicaid enrollees with dementia eligible for the NYUCI, 2011	
Mild dementia	1,043
Moderate dementia	2,507
Severe dementia	2,413
Total	5,963
Annual incidence of dementia in Medicaid enrollees, selected years	
1 (2012)	1,342
5 (2016)	1,516
10 (2021)	1,809
15 (2026)	2,153

Notes: People eligible for intervention include AC and EW enrollees aged 65–99 living in the community with a family caregiver. Prevalence of dementia among Medicaid enrollees was calculated from MN DHS long-term care screening assessments, eligibility, and claims data. Estimated prevalence across disease severity (mild, moderate and severe) was based on the Canadian Study of Health and Aging (Graham et al., 1997) and expert opinion. Annual incidence of dementia among Medicaid enrollees was based on the same sources and the epidemiology of dementia as observed in Rochester, Minnesota (Knopman et al., 2006; Kokmen et al., 1999) and Minnesota population projections (Minnesota Department of Administration, 2013).
NYUCI = New York University Caregiver Intervention; AC = Alternative Care; EW = Elderly Waiver; MN DHS = Minnesota Department of Human Services.

Transition Probabilities

Enrollees with dementia have an annual likelihood of moving between defined health states based on estimated probabilities of disease progression, permanent NH placement, or dying. As in our previous model, the likelihood of disease progression and NH placement was based on analyses of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) database (Morris et al., 1989; Neumann et al., 2001). We assumed, as has been observed in CERAD and other AD registries, that rates of institutionalization increased by disease severity but did not differ by duration in each disease stage (Neumann et al., 2001; Smith, O'Brien, Ivnik, Kokmen, & Tangalos, 2001). In the absence of similar data for non-AD dementia, we assumed the transitions as observed in CERAD applied to all persons with dementia.

We reduced the estimated probability of permanent NH placement for people whose caregivers received ECSS according to the results observed in the NYUCI trial (Mittelman et al., 2006). We adjusted the CERAD-based probabilities of institutionalization for the 28.3% reduced risk of placement compared with usual care controls reported for this intervention. We varied this effect size based on the variability in estimated risks in sensitivity analyses, shown in Table 2.

The annual probability of death was based on all-cause mortality rates observed among all MN DHS program enrollees in 2011. Given the observed high prevalence of dementia and other chronic conditions in this low-income population, we did not adjust further for an increased hazard of death due to dementia. These rates were assumed to apply to moderate and severe dementia cases and adjusted for mild disease based on the estimated likelihood of death by severity in CERAD (Neumann et al., 2001). We assumed that mortality was unaffected by the NYUCI.

Direct Care Costs

Since our model was developed to assess the impact of intervention from a state payer perspective, costs included the cumulative state and federally funded medical, facility, and waiver-program payments. We estimated age- and gender-specific per member per month payments for program and medical services in 2011 administrative claims for enrollees with dementia, by program and location of residence. Given movement between programs, enrollees and payments on their behalf were distributed by program type (AC, EW, NH), as first observed in 2011, and payments were adjusted for months of program enrollment.

Table 3 reports annualized estimated MN DHS payments by program and location of residence. As expected, program and total payments for institutionalized enrollees were substantially higher than payments for community-based enrollees, given additional facility fees for NH care. As observed by others, medical payments for NH residents were lower than medical payments for community-dwelling recipients (Kane, Wysocki, Parashuram, Shippee, & Lum, 2013). It has been hypothesized that this effect is due to better clinical management in the NH setting of common problems such as urinary tract infections, improved pharmaceutical adherence, and fewer avoidable accidents. We did not stratify payments by severity given data limitations and assumed these payments were not affected by the NYUCI.

NYUCI Intervention Costs

Costs to provide the NYUCI were based on time spent to provide ECSS as observed in the trial, adjusted to Minnesota implementation. Estimated time for providing the program in the first year was 29.9 h per caregiver and family, including counseling, follow-up, phone counseling, making

Table 2. Estimated annual probabilities of nursing home placement for eligible Minnesota Medicaid enrollees with dementia in the community with and without the NYUCI

Level of dementia		Probability of transition			
			With NYUCI		
				Sensitivity analyses	
In community (starting status)	In nursing home (transitioned status)	Without NYUCI	Base case analysis	Larger NYUCI Effect	Smaller NYUCI Effect
Mild	Mild	2.33%	1.68%	1.26%	2.24%
	Moderate	1.22	0.88	0.66	1.17
	Severe	0.16	0.12	0.09	0.15
Moderate	Moderate	6.22	4.53	3.53	5.97
	Severe	3.73	2.72	2.06	3.58
Severe	Severe	21.90	16.38	12.59	21.14

Notes: The probability of transition across health states was based on analyses of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) database (Morris et al., 1989; Neumann et al., 2001). The reduced probability of transition to the nursing home with the NYUCI was based on CERAD data and the reduced risk of institutionalization as observed in the NYUCI trial (Mittelman et al., 2006). Ranges used in sensitivity analyses were based on the reported 95% confidence interval surrounding the adjusted hazard for residential placement (Mittelman et al., 2006).
NYUCI = New York University Caregiver Intervention.

arrangements, bookkeeping and peer review. Time for ad hoc follow-up during the second and subsequent years was 12.4 hours. Counselor travel time was weighted to reflect Minnesota's distribution of urban, suburban and rural eligibles, averaging 1.52 h per session. We applied an hourly rate of $49.95 (Social Work Salaries, 2014), including 30.4% benefits (Employer Costs for Employee Compensation-September 2013, 2016) and 23% overhead, yielding costs of $1,948.45 for the initial year and $619.38 subsequently. We added varying counselor training and supervision costs based on the managerial model of the Minnesota translation of the NYUCI (Mittelman et al., 2010) scaled to statewide implementation.

Analysis

Using Monte Carlo microsimulation approaches, people with dementia progressed through the three model health states, incurring costs over 15 years (discounted 3% annually), with or without intervention. The model tracked program, medical and intervention costs separately. The impact of intervention on costs is also displayed at years 3, 5, and 10 to investigate the break-even point at which cumulative intervention costs are exceeded by cumulative savings. Lack of research makes projecting program uptake rates by eligible caregivers problematic. Program enrollment by caregivers in this population, where the affected individual is already receiving other supportive services, may be higher than in the general population. In the absence of a data-driven uptake rate, our base case results assume all eligible caregivers participate in the NYUCI; we also present results at varying levels of enrollment.

Additional univariate and scenario sensitivity analyses tested the strength of results. The model was programmed and analyzed in TreeAge Pro 2012 Healthcare software.

Table 3. Estimated annual Minnesota Medicaid payments by program and location of residence for enrollees with dementia

	Program payments	Medical payments	Total payments
Community			
Alternative Care	$12,216	Not eligible	$12,216
Elderly Waiver	$14,616	$11,484	$26,100
Nursing home	$45,672	$5,364	$51,036

Notes: Results are based on average 2011 per member per month payments in Minnesota Medicaid claims data. Program payments for community members vary at the individual level and include long-term care services such as home health and chore support and assisted living expenses for Elderly Waiver participants. Program payments for nursing home members represent long-term care facility fees paid by the Medicaid program.

Results

Our model predicts a 115% increase in the prevalence of MN DHS eligibles with dementia from 2011 to 2026 who initially were community-dwelling and resided with a spouse or adult child caregiver. Figure 1 shows the proportion of this growing population in each health state with and without the NYUCI. The proportion remaining community-dwelling rises 5.3% at year 3 with intervention, and that difference increased slightly going forward. For instance, the proportion remaining in the community increased from 52.7% to 58.6% at year 15. Additionally, after 15 years our model suggests approximately 17% fewer eligibles with dementia whose caregivers received the NYUCI will die in a NH setting (data not shown).

The projected cumulative net direct cost savings to MN DHS associated with intervention range from a loss of $6.4 million at year 3 to a savings of $40.4 million after 15 years (Table 4). At the population level, NH cost savings are substantial, ranging from $25.0 million at year 3 to $196.8 million at year 15, but these are partially offset by higher medical costs incurred with more people remaining in the community and no assumed per person cost savings with intervention for caregiving families. Substantial NYUCI program costs for counselor time, ongoing training, and administrative expenses also reduce savings, resulting in net losses until year 5. These results assume all eligible caregivers enroll; with lower program uptake, the net cost savings at 15 years are $28.3 million (70% enrollment), $20.2 million (50%), $12.1 million (30%), and $4.0 million (10%).

We performed sensitivity analyses on variables and methods of greatest uncertainty. Univariate analyses suggest the variability in net cost savings was most affected by the NYUCI's effect size. For instance, we varied the effect based on the estimated 95% confidence interval for the risk

DISTRIBUTION OF THREE HEALTH STATES AMONG ELIGIBLE MINNESOTA MEDICAID ENROLLEES, BY SELECTED YEARS OF ANALYSIS
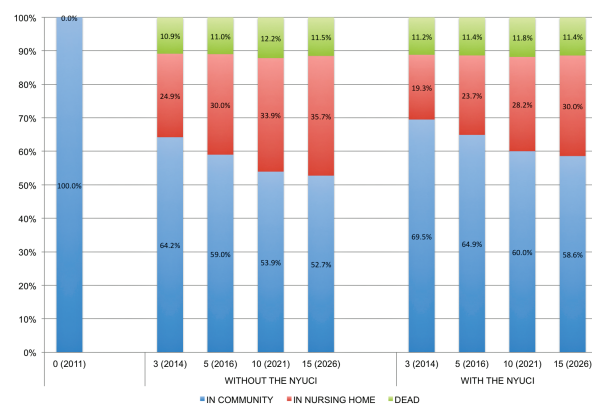

Figure 1. Results are based on authors' analysis of model results. Proportion of the population in each of three health states, with and without the NYUCI, by selected years of analysis, showing the increase with intervention in community-dwelling people with dementia. People eligible for the NYUCI were ages 65 to 99 who initially were living in the community with a spouse or adult child caregiver.

Table 4. Estimated cumulative net direct cost savings with NYUCI for eligible Minnesota Medicaid enrollees with dementia, by year ($)

Year	In community			In nursing home			All persons with dementia		
	Program costs	Medical costs	Subtotal costs	Program costs	Medical costs	Subtotal costs	Total program and medical costs	NYUCI intervention costs	Net total costs
3 (2014)	–4,946,305	–3,671,272	–8,617,577	25,010,428	3,815,404	28,825,832	20,208,255	–26,627,237	–6,418,982
5 (2016)	–11,545,503	–8,424,427	–19,969,930	50,751,196	7,714,695	58,465,891	38,495,961	–38,316,689	179,272
10 (2021)	–30,319,382	–21,778,827	–52,098,209	122,663,377	18,612,196	141,275,573	89,177,364	–67,671,778	21,505,586
15 (2026)	–51,050,437	–37,256,522	–88,306,959	196,761,059	29,831,844	226,592,903	138,285,944	–97,874,280	40,411,664

Notes: Results are based on authors' analysis of model results. All costs are in discounted 2011 dollars. Positive dollar values indicate estimated population-level savings with the NYUCI compared to without NYUCI. Negative dollar values indicate higher population-level costs with the NYUCI compared to without NYUCI. Results suggest substantial cumulative savings in nursing home costs are reduced by higher costs for more community-dwelling enrollees in the NYUCI and by NYUCI intervention costs, yielding net total cumulative costs savings from year 5 forward.

of residential placement (Mittelman et al., 2010). The net savings with intervention differed from –$74.5 million to $130.6 million, compared to the base case analysis result of $40.4 million. Other sensitivity analyses exhibited more limited impact on costs; undiscounted results were $51.4 million. Ways to provide the NYUCI via online delivery, eliminating counselor travel costs, are currently being investigated. Assuming this more cost-efficient approach, the net savings were $52.2 million.

We constructed best- and worst-case scenarios by varying several model inputs simultaneously. The best-case scenario assumed a larger intervention effect, video teleconferencing counseling approach, and undiscounted costs. The worst-case scenario assumed a smaller intervention effect, an in-person delivery mode with 10% higher counseling costs, and a 5% discount rate, as well as assuming that only 10% of eligible caregivers choose to enroll. Savings in these scenarios were $178.9 million and –$7.3 million, respectively, driven largely by the variation in the assumed NYUCI effect.

Implications

When we presented our statewide results from our Minnesota economic model of dementia, we were asked about program cost and specific payer perspectives. We address those questions in this model extension and, because of the difficulty of projecting caregiver enrollment rates, provide a range of estimates useful for program planning. Our model projects $40.4 million in cumulative MN DHS net savings over 15 years if the NYUCI were widely available and used. These savings remain substantial and robust to some alternative assumptions but are highly sensitive to intervention effect size. Savings are reduced, of course, at lower enrollment levels, but can be achieved even if there is no major breakthrough in the prevention or treatment of dementia.

Our model points to cumulative savings exceeding cumulative costs in year 5. This highlights the importance, as widely noted in health economic methods, of lengthy follow-up duration often needed to capture the benefits of interventions. This poses a challenge in American policy settings, where short time horizons for establishing return on investment—often tied to legislative cycles—are the norm for decision-making. Short time horizons risk dismissing the gradually emerging impact of interventions dealing with chronic diseases like dementia, the burden of which may become overwhelming for the caregiver only years after diagnosis.

Cost effectiveness may be a better metric, in fact, than return on investment to determine the value of an intervention such as the NYUCI, as increasingly recognized in the United States, because it incorporates morbidity, mortality, and direct and indirect costs associated with intervention (Neumann & Sanders, 2017). Since most state legislatures do not yet accept this perspective, we did not perform a cost-effectiveness analysis incorporating potential effects on mortality and quality of life associated with delayed institutionalization. Including these additional cost and caregiver outcomes might demonstrate different and additional NYUCI clinical and economic benefits.

These projected savings are driven by the established effectiveness of the NYUCI to improve caregiver wellbeing and thereby delay institutionalization, outcomes that promote the goals of the AC and EW programs. These impacts have a financial benefit for payers and society at large, and also are concordant with the wish of most persons with dementia and their caregivers to avoid or delay institutionalization. Consistent with this scenario, our model projects that after 15 years with intervention, 17% fewer eligibles would die in institutions.

Several studies have estimated dementia-attributable costs (Hurd et al., 2013; Leibson, et al., 2015), but formal estimates of the economic impact of non-pharmacologic intervention are rare (Knapp, Iemmi, & Romeo, 2013). Using a hypothetical cohort modeling approach, Weimer & Sager (2009) focused on the fiscal impact of combined early identification of AD followed by pharmaceutical treatment

and the NYUCI. They predict cost savings for both pharmacologic and non-pharmacologic therapies from varying perspectives, and conclude that savings are highest when cases are identified at earlier stages and with the synergistic effect of combined approaches. However, the efficacy of drug treatment remains controversial, and these authors assumed that caregiver support was equally effective in clinically diagnosed cases and in those identified by proactive screening, which is not the standard of practice in most clinical settings. Further, earlier identification may not be relevant to programs like AC and EW, whose enrollment targets individuals already at highest risk of institutionalization. Despite these differences, both our study and their work suggest positive economic benefits from a state payer perspective with ECSS.

As sensitivity analyses revealed, the net cost savings with intervention varies substantially based on assumptions surrounding effectiveness, highlighting the importance of fidelity in program design and implementation. For example, in 2015 Minnesota expanded its Medicaid waiver to include ECSS, based on the Family Memory Care Program demonstration project (Mittelman et al., 2010). An earlier analysis revealed that while translating the NYUCI in community settings with fidelity to the original model has proved challenging, program completion is linked to delayed institutionalization (Mittelman & Bartels, 2014). Uniform implementation of the NYUCI should be improved with online training and certification (Mittelman, Epstein, & Hobday, 2016).

The original study of the NYUCI was conducted among a lower to middle-class population with limited ethnic diversity and was based at an urban university hospital, raising the issue of generalizability. However, substantially delayed institutionalization was observed not just in the New York metropolitan area with spouse caregivers, but also in Minnesota with adult child caregivers, suggesting its generalizability (Gaugler et al., 2013). In addition, because lower income populations have higher rates of institutionalization, more opportunity may exist for the program to prevent NH placement (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996). Further research is warranted to test the generalizability of the NYUCI program.

The savings to a state also hinge on enrollment rates in the program and, as we noted previously, little evidence exists on this point. The enrollment rate in the NYUCI trial was not tracked, and this randomized controlled trial was not designed to predict uptake rates in a population. As with any social program, enrollment will depend on methods of marketing and recruitment. For instance, in the Minnesota Family Memory Care Program demonstration project, enrollment varied considerably across sites, depending on the skill and enthusiasm of the counselors involved in recruitment (Mittelman & Bartels, 2014). Further, cultural, demographic, and socioeconomic factors such as interest in counseling and levels of education and income may affect program enrollment rates, and also program completion and ultimately institutionalization.

Assumptions and Limitations

Assembling the parameters required for our model entailed several assumptions and limitations. Prevalence and incidence rates of dementia show considerable variation based on methods of ascertainment and sampling strategies (Brookmeyer et al., 2011). While we were able to estimate prevalence of dementia directly in our MN DHS population, our "passive surveillance approach" using administrative claims and screening assessments for case identification may underestimate true prevalence, particularly for cases of milder severity. Furthermore, without date of diagnosis we were unable to directly estimate annual incidence. As it is well-established that rates of dementia correlate inversely with income, we reasoned that it was not appropriate to apply other state or national estimates in this population (Meng & D'Arcy, 2012; Stern et al., 1994). Instead, we applied the ratio of incident to prevalent cases as observed in Rochester, Minnesota in combination with our observed MN DHS prevalence to estimate incidence rates. Further, while prevalence and incidence rates increase with age, they are generally considered unchanging over time, and our model follows this consensus. Recent studies raise the possibility that rates may be declining, which if borne out would decrease our projected net savings (Alzheimer's Association, 2016; Langa et al., 2016; Satizabal et al., 2016).

In the absence of information about dementia severity in MN DHS data sources, we assumed distributions across severity levels for epidemiologic parameters based on other sources and expert opinion. We also assumed that the transitions to NH observed in CERAD and in the NYUCI trial for AD patients applied to all people with dementia. We further assumed that the observed effectiveness of the NYUCI with spouse caregivers applied to adult child caregivers (Gaugler et al., 2013). The impact of these assumptions on results is unclear.

Our results apply to Minnesota, where the Medicaid program has specific eligibility rules, benefits, payment rates, clinical practice patterns, and other parameters that form a unique context in which to implement the NYUCI. Implementation and financial results in other states are likely to differ. Direct costs in our model assumed that patterns of care and Medicaid program eligibility requirements remain similar in the future. If the relative difference in direct costs between community and facility-based care change, our results would be affected. For instance, if the NYUCI empowered caregivers to better manage the health of the person with dementia, reducing medical payments in the community, estimated Medicaid savings would increase. Our model assumed no treatment breakthroughs that might alter the rate of transition to nursing facilities. However, as long as the trajectory of the disease continues to involve nursing facilities, some of the demonstrated benefits of ECSS—along with the financial savings we identify—would likely remain.

Given our state payer perspective, we did not account for other costs relevant to society and policymakers. For

instance, the indirect costs associated with time spent caregiving can exceed the direct costs we measured (Hurd et al., 2013). We also did not consider the positive indirect effects of ECSS on caregiver depression, physical health, and associated healthcare costs (Alzheimer's Association, 2016; Knapp et al., 2013; Schubert et al., 2008). Nationally, estimates suggest over 369,000 potentially avoidable hospital admissions occurred in 2013 among Medicare beneficiaries with AD and related dementias (Lin, Rane, Fillit, Cohen, & Neumann, 2016). Evidence is emerging that various clinical interventions, some with ECSS components, may be effective in reducing hospital admissions and re-admissions, with attendant cost savings (Morgan et al., 2015; Noel, Kaluzynski, & Templeton, 2015; MacNeil Vroomen et al., 2016).

Conclusions

ECSS can moderate the growing burden of dementia on government budgets, even without a breakthrough in pharmacologic treatment. But because it takes time to realize savings from a program like the NYUCI, the frequently short time horizon of legislative fiscal notes presents a challenge to adoption. In deciding on program value it may be important to distinguish cost-effectiveness from return on investment and take long-term impact into consideration.

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