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# The costs of treating all-cause dementia among American Indians and Alaska native adults who access services through the Indian Health Service and Tribal health programs

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#### Abstract

**Introduction:** Little is known about treatment costs for American Indian and Alaska Native (AI/AN) adults with dementia who access services through the Indian Health Service (IHS) and Tribal health programs.

**Methods:** We analyzed fiscal year 2013 IHS/Tribal treatment costs for AI/ANs aged 65+years with dementia and a matched sample without dementia (n=1842) to report actual and adjusted total treatment costs and costs by service type. Adjusted costs were estimated using multivariable regressions.

**Results:** Mean total treatment cost for adults with dementia were \$13,027, \$5400 higher than for adults without dementia (\$7627). The difference in adjusted total treatment costs was \$2943 (95% confidence interval [CI]: \$1505, \$4381), the majority of which was due to the difference in hospital inpatient costs (\$2902; 95% CI: \$1512, \$4293).

**Discussion:** Knowing treatment costs for AI/ANs with dementia can guide enhancements to policies and services for treating dementia and effectively using health resources.

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#### 1 INTRODUCTION

All-cause dementia is one of the most costly conditions in the United States1 and afflicted 11.5% of Medicare enrollees aged 65+ years in 2014.<sup>2</sup> Health costs for medical and long-term care services for US adults with all-cause dementia, excluding costs associated with informal caregiving, were estimated to be \$355 billion in 2021.<sup>3</sup> While Medicare and Medicaid are expected to pay for 67% of these costs, approximately 22% of remaining costs are household out-of-pocket costs.<sup>3</sup> Numerous studies found higher expenditures for patients with dementia than for those without dementia;<sup>4–8</sup> adjusted annual differences in expenditures ranged from \$3000 to \$13,000 in 2017 dollars.<sup>4–6,8</sup> Dementia treatment costs were higher for patients living in institutional settings, with greater functional limitations, and more chronic comorbidities.<sup>8–10</sup>

Furthermore, limited information exists about treatment costs for older AI/ANs who access services through the Indian Health Service (IHS), <sup>17–20</sup> which includes IHS and Tribal hospitals and clinics and urban Indian health clinics. IHS serves approximately 2.6 million AI/ANs in the United States. <sup>21</sup> An analysis of Medicare expenditures for AI/Ans who accessed IHS services in 2010 revealed lower per capita Medicare expenditures for AI/ANs compared to non-Hispanic White enrollees. <sup>19</sup> Within IHS, resources have been historically strained. <sup>22</sup> For example, in fiscal year (FY) 2019, IHS per capita spending was \$4078.21 While this amount does not include all spending associated with patient care, it is substantially lower than per capita spending for the US general population (\$11,582) in 2019. <sup>23</sup> IHS resources are further compromised by provider shortages and community-level factors that influence patient access to services (e.g., low household income, rural geography) <sup>22,24–26</sup>—characteristics that present challenges for treating chronic conditions.

To improve understanding of resources allocated to providing health care for this underserved population and inform strategies to effectively use such resources, here we describe treatment costs for AI/ANs with all-cause dementia who access HIS services.

### 2 METHODS

#### 2.1 Data source

The study population included AI/AN members of federally recognized Tribes who have lifetime access to IHS services (e.g., inpatient, outpatient, home services) at no cost, regardless of health coverage. Our study extracted data from the IHS Improving Health Care Delivery Data Project (IHS Data Project) that includes a purposeful sample of AI/ANs who lived in 15 IHS Service Units (hereafter referred to as project sites), which are geographic classifications located

throughout the United States. The IHS Data Project population was identified by geographic area, rather than by random sampling, to create important site treatment cost measures that are not available elsewhere (e.g., service cost estimates described below). The IHS electronic data sources included in the IHS Data Project's data infrastructure are the: (1) National Data Warehouse (NDW) for the adults' IHS/Tribal (I/T) use data, (2) Purchased/Referred Care (PRC) program for the adults' PRC use and payment for services obtained elsewhere (non-I/T services), and (3) Centers for Medicare & Medicaid Services (CMS) Cost Reports for Service Unit data on costs of providing I/T services. The IHS Data Project population is comparable to the national IHS service population in terms of age and sex.<sup>27</sup>

Project personnel partnered with IHS and Tribal organizations participating in the IHS Data Project via the project's Collaborative Network, which includes regular meetings of three advisory committees (i.e., Steering, Project Site, and Patient), travel to the project sites, and a process to obtain approvals from the HIS National Institutional Review Board (IRB), Tribal IRBs, and Tribal authorities in addition to the University of Colorado's IRB.

### 2.2 Study population

The study population included a 1:1 matched sample of 1842 AI/AN adults aged 65+ years (921 with all-cause dementia and 921 controls) matched on birth year ( $\pm$  1 year), sex, and project site, using the Mayo Clinic's GMATCH macro.28 We did not match on health coverage or health status because a focus of this analysis was on understanding the influence of health coverage and comorbidities on costs.

Using International Classification of Diseases 9th Revision Clinical Modification (ICD-9) diagnostic codes recorded in the NDW and PRC inpatient and outpatient use records, we identified adults as having all-cause dementia if they were assigned at least one qualifying ICD-9 code for all-cause dementia during FY2007–2013.29 The qualifying ICD-9 codes included Alzheimer's disease (AD), vascular, Lewy body, frontotemporal, alcohol-induced, and other types of dementia used in a recent Medicare study (see Table S1 in supporting information). The individuals lived in one of 10 project sites and used IHS services during FY2013 (i.e., between October 1, 2012 and September 30, 2013). These project sites represent four regions of the United States: East, Northern Plains, Southern Plains, and Southwest.30 Five of the 15 sites were excluded due to missing data; two had incomplete pharmacy cost data, two had incomplete PRC cost data, and one had missing cost data for all services. Nearly all the study population lived in the community, only a few lived in an institutional setting.

### 2.3 Measures

### 2.3.1 Demographic and health coverage

NDW data provided information on age, sex, project site, and type of health coverage (e.g., Medicare, Medicaid, private insurance).

### 2.3.2 Health status

We used two methods to create additional dichotomous chronic condition variables. A validated algorithm, based on ICD-9 codes, medication codes, and blood sugar values, was used

to identify adults with diabetes.<sup>31</sup> Sightlines DxCG Risk Solutions software was used to identify adults with other chronic conditions (e.g., CVD, mental health disorders) based on diagnostic codes.<sup>32</sup>

### 2.3.3 Treatment costs

FY2013 IHS treatment cost estimates were derived from FY2013CMS Cost Report data, FY2013NDWI/T use data, and FY2013 PRC administrative data for services paid by IHS and Tribal health programs. Each fiscal year, IHS financial consultants compile data on the costs of operating the I/T hospitals and clinics, using government accounting practices, in the CMS Cost Reports. The Cost Report I/T data are used to create Medicare and Medicaid reimbursement rates for I/T-provided services (i.e., one inpatient day, one outpatient visit). The Cost Reports include Service Unit costs for personnel salaries and benefits, facilities, equipment, operational costs (e.g., heating, electricity), supplies, and medications.

To estimate site-specific costs for a wide array of I/T services (e.g., one inpatient day; one emergency, primary care, or specialty care visit; one dispensed medication), Cost Report and NDW data were supplemented by project site information. Treatment costs for I/T-provided services for each adult were estimated based on their use of I/T services and the estimated average cost of providing each of those services in the site where they lived. PRC-paid amounts were used to estimate costs for non-I/T services. Hereafter, we refer to IHS total treatment costs for each adult as the sum of their estimated costs for I/T and non-I/T-provided services.

We analyzed total treatment costs by four service categories: hospitalization (i.e., inpatient stays), hospital emergency department (ED), outpatient excluding ED, and pharmacy (e.g., prescribed medications). Costs for services from non-I/T providers that were not paid by the PRC program (e.g., specialty inpatient and outpatient services, renal dialysis)were not available and, thus, not included. These analyses also exclude Tribal costs associated with many home visits and nearly all nursing home services. More information on the IHS Data Project data infrastructure is reported elsewhere27 (see supporting information).

### 2.4 Analysis

Differences in health coverage and health status between adults with and without dementia were compared using Pearson Chi-squared tests. Based on preliminary data analyses and testing, we used a generalized linear model (GLM) with a log link function and gamma distribution to estimate the adjusted difference in FY2013 IHS total treatment, outpatient, and pharmacy costs between adults with and without dementia controlling for health coverage (e.g., Medicaid, private insurance) and health status (e.g., diabetes, CVD, mental health disorders).

The percentage of adults with zero costs for these measures were 0%, 2.8%, and 11.9%, respectively. Due to a high percentage of adults with zero hospitalization (78.1%) and ED (55.5%) costs, we used a two-part model for these services that consisted of a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. <sup>4,5,7</sup> The 95% confidence intervals (CIs) for the mean differences in inpatient and ED costs between adults with and without dementia were estimated via bootstrapping using 1000 simulations. All costs are presented as mean with 95% CIs.

For each type of cost, we used a series of regression models to estimate adjusted costs and understand how groups of covariates, when added sequentially to the models, influenced the estimated difference in costs between adults with and without dementia. Model 1 controlled for health coverage because health coverage increases a patient's financial access to non-I/T services and likely serves as a proxy measure of the patient or household income or employment status, both of which have been associated with health service use and costs. For example, Medicaid enrollment usually indicates low household income.

The health status measures were selected based on their prevalence among older AI/AN adults, prior knowledge and experience analyzing their association with health service use and costs, and findings from other studies. For example, AI/ANs have high prevalence of diabetes and related comorbidities. Model 2 added five cardiometabolic conditions (diabetes, CVD, hypertension, chronic kidney disease, and amputations) to Model 1. Model 3 added behavioral health conditions (mental health, alcohol and drug use, and tobacco use disorders) to Model 2. Model 4 added two other conditions, malignant cancer and liver disease, to Model 3 and is considered the fully adjusted model.

### 3 RESULTS

In FY2013, 981 AI/AN adults aged 65+ years with all-cause dementia were identified. We matched 921 (93.9%) of them with adults without dementia. The other 60 adults with dementia, who were not matched because no adult of similar age and sex without dementia could be found at their site, were excluded from the study. Nearly 90% of the unmatched adults were aged 80 years and older.

Study population characteristics are presented in Table 1. Approximately 60% of adults with dementia were female. About one-quarter were aged 65 to 74 years, 44.6% were 75 to 84 years, and 30.2% were  $\geq$  85 years. Most resided in the Southwest or Southern Plains.

Over 95% of the study population had Medicare coverage. More adults with dementia had Medicaid coverage (18.1% vs. 9.6%, P<.001), while more adults without dementia had private insurance (7.7% vs. 10.9%, P<.05). More than 97% of adults with Medicaid coverage were dually enrolled in Medicare. Similarly, 98.2% of adults with private insurance also had Medicare coverage.

**TABLE 1** Population characteristics of American Indian and Alaska Native adults aged 65 years and older with and without dementia. Fiscal year 2013

	Withdem	entia	Without	lementia		
	#	Percent (column)	#	Percent (column)	Chi square P-value	
All adults aged 65+ years	921	100.0	921	100.0		
Characteristics matched on						
Female	552	59.9	552	59.9		
Age						
65-74	232	25.2	237	25.7		
75-84	411	44.6	407	44.2		
85+	278	30.2	277	30.1		
Region*						
East	92	10.0	92	10.0		
Northern Plains	165	17.9	165	17.9		
Southern Plains	255	27.7	255	27.7		
Southwest	409	44.4	409	44.4		
Health coverage						
Medicare	887	96.3	897	97.4	.18	
Medicaid	167	18.1	88	9.6	<.0001	
Private coverage	71	7.7	100	10.9	.02	
No coverage other than access to IHS/Tribal services	27	2.9	20	2.2	.30	
Health status						
CVD	601	65.3	472	51.3	<.0001	
Diabetes	508	55.2	451	49.0	.01	
Hypertension	722	78.4	688	74.7	.06	
Renal disease	274	29.8	191	20.7	<.0001	
Amputation	25	2.7	15	1.6	.11	
Mental health disorder	375	40.7	172	18.7	<.0001	
Alcohol/druguse disorder	83	9.0	21	2.3	<.0001	
Tobacco use disorder	65	7.1	41	4.5	.02	
Liver disease	73	7.9	34	3.7	.0001	
Malignant cancer	90	9.8	82	8.9	.5218	

Abbreviation: CVD, cardiovascular disease.

In general, adults with dementia had a higher prevalence of chronic diseases than those without dementia. They had a higher prevalence of CVD (65.3% vs. 51.3%, P < .001), diabetes (55.2% vs. 49.0%, P < .01), and chronic kidney disease (29.8% vs. 20.7%, P < .001), as well as mental health (40.7% vs. 18.7%, P < .001), alcohol and drug (9.0% vs. 2.3%, P < .001), and tobacco use disorders (7.1% vs. 4.5%, P < .05).

As shown in Table 2, mean total treatment cost for adults with dementia was \$13,027, which was \$5400 (\$3662–\$7138) higher than that for adults without dementia (\$7627). In the fully adjusted model, adults with dementia had \$2943 (\$1505–\$4381) higher total treatment costs.

<sup>\*</sup>Adults with dementia were matched with adults without dementia by age, sex, and project site. Project sites are located within regions.

**TABLE 2** Unadjusted and adjusted treatment costs (in US dollars) for American Indian and Alaska Native adults aged 65 years and older with and without dementia. Fiscal year 2013

	Unadjuste	dCosts				
	With deme	entia	Without	dementia	Differenc	e
	Mean	SD	Mean	SD	Mean	95% CI
Total treatment costs	13,027	20,686	7627	14,914	5400	(3662, 7138)
Treatment costs by service type						
Hospital inpatient costs	6621	18,339	2285	11,600	4336	(2938, 5734)
Hospital ED costs	1006	1773	519	1104	487	(355, 620)
Outpatient costs (excluding ED costs)	3649	4618	3243	5013	406	(-39, 851)
Medication costs	1751	1792	1580	1524	171	(19, 322)
	Adjusted c	osts (Model 4, fully adj	usted model	)-		
	Mean	95% CI	Mean	95%CI	Mean	95% CI
Total treatment costs	11,698	(10,521, 12,875)	8755	(7767, 9742)	2943	(1505, 4381)
Treatment costs by service type						
Hospital Inpatient costs†	5697	(4612, 6782)	2795	(1938, 3652)	2902	(1512, 4293)
Hospital ED costs <sup>†</sup>	852	(759, 944)	651	(564, 737)	201	(79, 323)
Outpatient costs (excluding ED costs)	3310	(3054, 3565)	3644	(3331, 3958)	-334	(-729, 61)
Medication costs	1664	(1554, 1773)	1713	(1592, 1835)	-50	(-208, 109)

Abbreviations: CI, confidence interval; ED, emergency department; SD, standard deviation. \*Unless otherwise noted, adjusted costs were estimated using a generalized linear model with a gamma distribution and a log link function, using Model 4 (the fully adjusted model) that controlled for health care coverage and all measures of health status.

<sup>†</sup>Due to a high percentage of adults with zero costs, the mean adjusted cost difference was estimated using a two-part model. The first part used a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. The Cis for the mean differences between adults with and without dementia were estimated via bootstrapping using 1000 simulations.

Note: Bolded estimates and 95% CIs are significant because zero is not included with the 95% CI.

Hospital inpatient costs were \$6621 for adults with dementia, representing 50.8% of total treatment costs. Among adults without dementia, this percentage was 30.0%. Differences in adjusted hospital inpatient costs explained much of the difference in adjusted total treatment costs between adults with and without dementia; the difference in adjusted hospital inpatient costs was \$2902 (\$1512–\$4293). Hospital ED costs, which accounted for 6.6% of total treatment costs for adults with dementia, were higher for adults with dementia (\$852) than those without dementia (\$651); the difference in adjusted ED costs was \$201 (\$79–\$323).

Costs for other types of outpatient services were \$3649 among adults with dementia and \$3243 among adults without dementia accounting for 28.0% and 42.5%, respectively, of their total treatment costs. Prescribed medication costs for adults with dementia (\$1751) and without dementia (\$1580) accounted for 13.4% and 20.7%, respectively, of their total treatment costs. We found no statistical difference in adjusted estimates for these two types of costs by dementia status. Figure 1 and Table 3 illustrate treatment costs for adults with and without dementia after adjusting for each set of covariates in the four regression models used to estimate adjusted costs. The difference in unadjusted total treatment costs was \$5400 (Figure 1A). This difference was

\$5009 (\$391 less) when only adjusting for health coverage (Model 1). Model 2, which included cardiometabolic conditions, estimated a difference of \$3338 (1671 less than Model 1). When adding behavioral health disorders (Model 3), the difference in adjusted total costs was \$2681 (\$657 less than Model 2). For Model 4, which included two other conditions, differences in adjusted total treatment were estimated to be \$2943 (\$395 less than Model 3).

**TABLE 3** Differences in treatment costs (in US dollars) between American Indian and Alaska Native adults with and without dementia. Unadjusted and adjusted\* total treatment costs and costs by service type. Fiscal year 2013

	Difference in treatment costs between adults with and without dementia										
	Hospital costs <sup>†</sup>		ED costs <sup>†</sup>		Outpatient costs		Medication costs		Total treatment costs		
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	
Unadjusted (actual) costs	4336	(2937, 5734)	487	(355, 620)	406	(-39, 851)	171	(19, 322)	5400	(3662, 7138	
Adjusted costs											
Model 1: Health coverage	4054	(2675, 5434)	456	(322, 589)	330	(-121, 782)	164	(12, 317)	5009	(3328, 6690	
Model 2: Model 1 + cardiometabolic conditions	3149	(1784, 4514)	353	(227, 479)	-76	(-471, 319)	58	(-97, 214)	3338	(1936, 4740	
Model 3: Model 2 + behavioral health conditions	2953	(1532, 4374)	209	(87, 330)	-348	(-739, 44)	-51	(-210, 108)	2681	(1239, 4122	
Model 4: Model 3 + liver disease and malignant cancer	2902	(1512, 4293)	201	(79, 323)	-334	(-729, 61)	-50	(-208, 109)	2943	(1505, 4381	

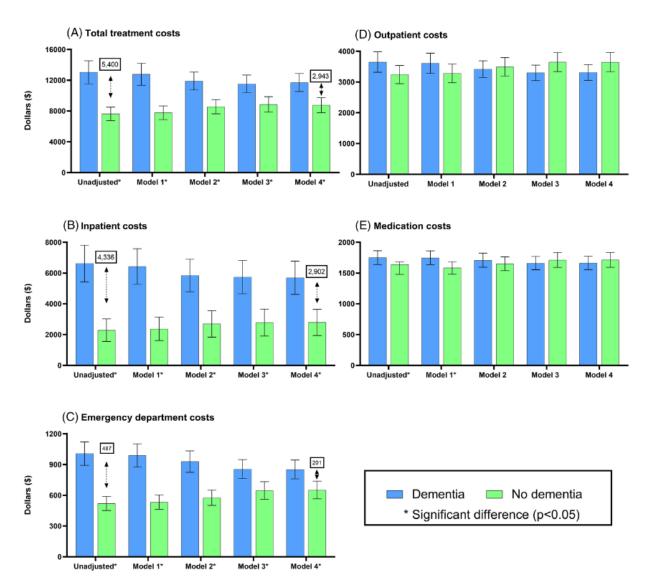
Abbreviations: CI, confidence interval; CVD, cardiovascular disease; ED, hospital emergency department.

\*Regression Models 1—4 adjusted incrementally for health coverage and health status. Unless otherwise stated, adjusted costs were estimated using a generalized linear model with a gamma distribution and a log link function.

†Due to a high percentage of adults with zero costs, the mean adjusted cost difference was estimated using a two-part model. The first part used a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. The CIs for the mean differences between adults with and without dementia were estimated via bootstrapping using 1000 simulations.

Note: Bolded estimates and 95% CIs are significant because zero is not included with the 95% CI.

Similar to total treatment costs, the adjusted difference in hospitalization costs (Figure 1B) between adults with and without dementia generally decreased across Models 1 through 4, as we controlled for more differences between the two samples. The difference in adjusted hospital costs, using Model 4, were \$2902 (\$1512–\$4293). As with total treatment costs, the largest decrease across the four models in hospitalization costs was associated with the inclusion of the cardiometabolic conditions in Model 2—a decrease of approximately \$900.



**FIGURE 1** Unadjusted and adjusted treatment costs for American Indian and Alaska Native adults with and without dementia. Total treatment costs (Figure 1A) and treatment costs by service type (Figures 1B-E). US dollars, fiscal year 2013. The unadjusted costs are actual costs. Models 1-4 costs are adjusted costs that control for differences between adults with and without dementia. Model 1 controlled for differences in health coverage. Model 2 controlled for health coverage and cardiometabolic conditions. Model 3 controlled for the same measures as Model 2 plus behavioral health conditions. Model 4 controlled for the same measures as Model 3 plus liver disease and malignant cancer

The impact of specific comorbidities on total treatment costs among all adults varied, with CVD, diabetes, chronic kidney disease, and liver disease having the largest impact (Table 4). The difference in total treatment costs associated with specific comorbidities (i.e., the average marginal cost) was \$5156 (\$3785–\$6528) for CVD; \$4782 (\$2718–\$6845) for chronic kidney disease; \$3823 (\$2405–\$5240) for diabetes; and \$7885 (\$2831–\$12,940) for liver disease. Because adults with dementia had a higher prevalence of these four conditions, these conditions contributed to the higher total treatment costs for patients with dementia.

**TABLE 4** Adjusted differences in treatment costs (in US dollars) associated with health coverage and health status between American Indian and Alaska Native adults aged 65 years and older with and without dementia. Total treatment costs and costs by service type. Fiscal year 2013

	Hospital costs†		ED costs†		Outpatient costs		Medication costs		Total treatment costs	
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI
Dementia	2902	(1512, 4293)	201	(79, 323)	-334	(-729, 61)	-50	(-208, 109)	2943	(1505, 4381)
Health coverage										
None	2840	(-2385, 8066)	-343	(-585, -101)	1,102	(-453, 2658)	-129	(-578, 320)	678	(-4082, 5437
Medicaid	3707	(1084, 6331)	349	(154, 545)	843	(204, 1482)	180	(-58, 418)	6042	(3098, 8986)
Private	315	(-2082, 2713)	-185	(-384, 14)	-45	(-672, 583)	-113	(-360, 135)	-1222	(-3417, 973)
Cardiometabolic conditions										
Hypertension	-432	(-2244, 1380)	-164	(-336, 8)	670	(261, 1080)	727	(586, 869)	1121	(-508, 2750)
Diabetes	1137	(-225, 2499)	199	(77, 320)	1,380	(1001, 1760)	779	(625, 933)	3823	(2405, 5240)
CVD	3195	(1789, 4601)	396	(273, 520)	1,120	(729, 1510)	560	(405, 715)	5156	(3785, 6528)
Renal	3341	(1547, 5135)	176	(13, 339)	846	(328, 1365)	206	(7, 404)	4782	(2718, 6845)
Amputation	2630	(-4187, 9447)	165	(-216, 545)	334	(-1057, 1726)	-220	(-682, 242)	2786	(-3318, 889
Behavioral health conditions										
Mental health disorders	873	(-555, 2300)	402	(242, 562)	1,187	(712, 1662)	403	(215, 591)	2467	(750, 4183)
Alcohol/drug use disorders	595	(-1605, 2794)	667	(202, 1131)	477	(-454, 1409)	200	(-172, 571)	1552	(-1948, 5052
Tobacco use disorders	-1514	(-3538, 510)	-138	(-350, 73)	-564	(-1255, 128)	204	(-160, 568)	-1926	(-4518, 665)
Other conditions										
Liver disease	6247	(1892, 10603)	367	(81, 653)	1,068	(44, 2092)	126	(-225, 477)	7885	(2831, 12940
Malignant cancer	1321	(-856, 3499)	152	(-79, 384)	1.029	(235, 1823)	354	(47, 662)	3683	(558, 6807)

Abbreviations: CI, confidence interval; CVD, cardiovascular disease; ED, hospital emergency department.

\*The differences in adjusted treatment costs were estimated from Model 4, the fully adjusted model, that included health coverage and all health status measures. The estimated difference, or average marginal

cost, describes the influence on costs associated with the measure of health coverage or health status. Unless otherwise noted, adjusted costs were estimated using a generalized linear model with a gamma distribution and a log link function.

†Due to a high percentage of adults with zero costs, the mean adjusted cost difference was estimated using a two-part model. The first part used a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. The CIs for the mean differences between adults with and without dementia were estimated via bootstrapping using 1000 simulations.

Note: Bolded estimates and 95% CIs are significant because zero is not included with the 95% CI.

#### **4 DISCUSSION**

We found the unadjusted total treatment costs for AI/AN adults with all-cause dementia were \$5400 higher than that for similarly aged adults without dementia; this difference accounted for approximately 40% of the former's total treatment costs (\$13,027) in FY2013. The adjusted difference in treatment costs was found to be nearly \$3000, after adjusting for costly comorbidities such as CVD, renal disease, and diabetes; most of this difference was accounted for by the adjusted difference in hospital inpatient costs. We compared our FY2013 IHS cost estimates to costs for a similarly aged sample of community-dwelling US adults from the

Medical Expenditure Panel Survey.<sup>5</sup> Annual treatment costs for US adults with dementia totaled \$17,032 in 2013 dollars. The adjusted difference in treatment costs between those with and without dementia was approximately \$4400. However, home health expenditures accounted for most of this difference (\$2852). No differences were found in use or costs for inpatient services, and inpatient expenditures accounted for only 23.9% of all expenditures, excluding those for home health. In our study, hospital inpatient services accounted for nearly all the difference in adjusted total costs between patients with and without dementia (\$2902). It is difficult to compare our treatment cost estimates to those reported for adults with Medicare coverage, calculated using Medicare expenditure data, because Medicare data typically include data for both community-dwelling adults and adults living in institutional settings.

Two findings from our study highlight important policy, health system, and future research opportunities. First, hospital inpatient costs accounted for not only most of the adjusted differences in total treatment costs between adults with and without dementia, but also half of total treatment costs for AI/ANs with dementia. While previous studies have reported higher hospital inpatient use and costs among adults with dementia, compared to those without dementia, 8,33-36 the relative magnitude of resources allocated to hospital inpatient care among AI/ANs with dementia in this study is striking. Dementia studies found hospital service use was associated with greater chronic disease burden, more functional limitations, higher drug use, and lower use of home-based or coordinated care services.<sup>37–39</sup> Furthermore, a sizable percentage of inpatient admissions and ED visits among Medicare dementia patients were found to be potentially preventable. 35,36 Nearly 30% of adjusted hospital inpatient expenditure differences between community-dwelling Medicare beneficiaries with and without dementia were deemed preventable.33 Future research directions include examining reasons for higher inpatient and ED use by AI/Ans with dementia, preventable reasons for such use, and how social determinants of health are associated with inpatient and ED use. The high costs of treating AI/AN adults with dementia in hospital inpatient and ED settings suggest that outpatient and community-based strategies to prevent unnecessary use of these services may improve health outcomes and reduce resources for their provision<sup>39–42</sup>—resources that could partially support implementation of those strategies.

Second, AI/AN adults with dementia had a higher prevalence of costly chronic conditions than those without dementia (e.g., diabetes, CVD, renal disease). The prevalence and treatment costs associated with these conditions contributed to differences in total, hospital inpatient, and ED treatment costs between adults with and without dementia and illustrate the complexity of caring for these patients. Previous studies have shown that more co-occurring chronic conditions increase expenditures, 8-10 and the prevalence of several chronic conditions among the AI/AN adults with dementia in our study were higher than rates reported for Medicare enrollees with dementia.<sup>7,8</sup> Significant drivers of cost differences by race/ethnicity among Medicaid enrollees with AD were associated with chronic disease burden and use of inpatient hospital and long-term care services. There is strong evidence that Black adults with dementia had higher use of hospital inpatient services than US comparison populations with two of the four studies<sup>43</sup> showing higher rates of chronic disease in Black adults. Future research on the relationship between racial/ethnic disparities in health status and high inpatient costs among adults with dementia is necessary. Taken together, these findings suggest that to avoid costly inpatient stays additional resources should be allocated to outpatient and homebased care management among AI/ANs with dementia. Research on relationships among use of collaborative care models, care

coordination, continuity of care, and home-based services with reduced hospitalizations and costs is promising.

Providing care for AI/AN dementia patients is further challenged by social determinants coupled with constraints on provider time and resources available. Nearly half of AI/ANs with dementia in our study resided in rural counties (Table S2 in supporting information)<sup>44</sup> and in counties where 47.3% of AI/AN households, whose member(s) accessed IHS services, had incomes below the federal poverty level, and 35.0% of adults did not have a high school degree45 (Table S2). In a recent national study,3 42% of Native American adults reported experiencing discrimination when seeking health care. Approximately 90% said it was important that AD and dementia care providers understand AI/AN patients' racial/ethnic background and experiences when providing treatment.

To address these needs, many Tribes and IHS have implemented programs in a culturally appropriate manner that include educating primary care providers and developing guidelines on dementia warning signs, screening, and treatment and providing support to caregivers of AI/ANs with dementia. An number of Tribes created dementia-capable communities by increasing knowledge on dementia and community-based screening. Increasingly, Tribes are providing patient care management and home-based caregiver services. Active Additionally, there are 18 Tribal nursing homes with approximately 950 beds. Despite these noteworthy efforts, access to such services is limited. In 2012, 41.6% of older White Medicaid enrollees used long-term institutional care and home and community-based services, while only 16.3% of older AI/AN Medicaid enrollees who used IHS services did.

This study has several limitations. The data used in this study are specific to community-dwelling older AI/AN adults; in general, they exclude costs for those in residential settings. We reported treatment costs for adults diagnosed with dementia, excluding those with undiagnosed dementia. As health expenditures vary by dementia severity, <sup>10</sup> these two limitations likely influenced costs in opposite directions. The number of undiagnosed adults is influenced by resource constraints of a health system that provides services for AI/ANs who reside in rural areas with limited access to services, <sup>22</sup> including specialists, and who may have limited knowledge of dementia. While these data allowed us to examine dementia costs for a large number of older AI/ANs, we identified adults with dementia using diagnostic codes recorded in service use records, <sup>29</sup> which did not include medication data and was less detailed than information available from medical record reviews or other health assessments. For 60 adults with dementia, we could not identify a matched adult without dementia. However, based on analyses of health expenditures by age, we estimated their inclusion in the study population would have had a very minimal influence on our study findings.

We did not have data for services from non-I/T providers not paid for by the PRC program (e.g., specialty inpatient and outpatient, renal dialysis) nor for Tribal costs for most home visits, nearly all nursing home costs, or hospice care. We did not have cost data for the entire fiscal year for some adults because some may have moved away or died, nor did we have data to estimate the influence of these changes. In addition, sites varied by the types of I/T services provided, access to non-I/T services, PRC use, and data completeness. Thus, the costs reported here under-represent treatment costs for all types of services and do not include costs for informal care. However, they represent the costs of providing care within the IHS service delivery system. Last, although our results are generalizable to the adults who lived in the 10 project sites, representing a geographically dispersed population of AI/AN adults, our findings

may not reflect the health status of AI/AN peoples who live elsewhere or who do not obtain health services through IHS or Tribal programs.<sup>26</sup>

Despite these limitations, this study is the first to document treatment costs for AI/ANs with dementia compared to those without dementia, among a geographically dispersed population of AI/Ans who seek services through IHS and Tribal health programs. Approximately half lived in rural counties, which are usually under-represented in other AI/AN dementia studies. The overwhelming majority of adjusted differences in treatment costs were associated with hospital inpatient services. Not only is there a need to assess reasons for the hospitalizations of dementia patients, we also need to assess resources allocated to services that may prevent them, particularly due to the financial constraints of IHS and Tribal health programs and the rural location of approximately half of their patients with dementia. Tribal access to innovative state and CMS reimbursement programs for long-term care services and support will likely increase care options for AI/ANs with dementia and their families. Additionally, resources allocated to prevent and treat risk factors for dementia may not only reduce dementia risk among AI/AN adults but also reduce resources required to treat those with dementia.

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#### CONFLICTS OF INTEREST

The authors have no disclosures to report.

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### SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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#### RESEARCH IN CONTEXT

- 1. Systematic review: The authors conducted a literature review using PubMed, Google Scholar, and other sources. American Indian and Alaska Native (AI/AN) adults who obtain health care from the Indian Health Service (IHS) or Tribal health programs are at high risk of dementia due to their morbidity burden. Little is known about IHS/Tribal costs of treating dementia, information that may guide enhancements to health policies and services and effective use of limited resources.
- 2. Interpretation: AI/ANs with dementia had higher total treatment costs than AI/ANs without dementia. Much of this difference was due to adults with dementia having higher costs for hospital inpatient and emergency department services. These results suggest opportunities exist for enhancing dementia non-emergency outpatient, community, and home services that could reduce potentially preventable hospital costs.
- 3. Future directions: Future studies are needed to identify risk factors (e.g., health, social determinants of health) for potentially preventable hospital use.

### HIGHLIGHTS

- Older American Indian and Alaska Native (AI/AN) adults are at high risk of dementia.
- Little is known about the Indian Health Service's (IHS) costs for treating AI/ANs with dementia.
- IHS total treatment costs for AI/ANs with dementia are higher than those of AI/ANs without dementia.
- Higher hospitalization costs for AI/ANs with dementia accounted for nearly all of this difference.
- Dementia treatment cost findings for AI/ANs may inform enhancements to IHS services for adults with dementia.

**TABLE 3** Differences in treatment costs (in US dollars) between American Indian and Alaska Native adults with and without dementia. Unadjusted and adjusted\* total treatment costs and costs by service type. Fiscal year 2013

	Difference in treatment costs between adults with and without dementia											
	Hospital costs <sup>†</sup>		ED costs <sup>†</sup>		Outpatient costs		Medication costs		Total treatment costs			
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI		
Unadjusted (actual) costs	4336	(2937, 5734)	487	(355, 620)	406	(-39, 851)	171	(19, 322)	5400	(3662, 7138)		
Adjusted costs												
Model 1: Health coverage	4054	(2675, 5434)	456	(322, 589)	330	(-121, 782)	164	(12, 317)	5009	(3328, 6690)		
Model 2: Model 1 + cardiometabolic conditions	3149	(1784, 4514)	353	(227, 479)	-76	(-471, 319)	58	(-97, 214)	3338	(1936, 4740)		
Model 3: Model 2 + behavioral health conditions	2953	(1532, 4374)	209	(87, 330)	-348	(-739, 44)	-51	(-210, 108)	2681	(1239, 4122		
Model 4: Model 3 + liver disease and malignant cancer	2902	(1512, 4293)	201	(79, 323)	-334	(-729, 61)	-50	(–208, 109)	2943	(1505, 4381		

Abbreviations: CI, confidence interval; CVD, cardiovascular disease; ED, hospital emergency department.

†Due to a high percentage of adults with zero costs, the mean adjusted cost difference was estimated using a two-part model. The first part used a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. The CIs for the mean differences between adults with and without dementia were estimated via bootstrapping using 1000 simulations.

Note: Bolded estimates and 95% CIs are significant because zero is not included with the 95% CI.

<sup>\*</sup>Regression Models 1–4 adjusted incrementally for health coverage and health status. Unless otherwise stated, adjusted costs were estimated using a generalized linear model with a gamma distribution and a log link function.

**TABLE 4** Adjusted differences in treatment costs (in US dollars) associated with health coverage and health status between American Indian and Alaska Native adults aged 65 years and older with and without dementia. Total treatment costs and costs by service type. Fiscal year 2013

	Difference	in adjusted treatmer	nt costs (Mod	el 4, fully adjusted m	odel)					
	Hospital costs†		ED costs†		Outpatient costs		Medication costs		Total treatment costs	
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI
Dementia	2902	(1512, 4293)	201	(79, 323)	-334	(-729, 61)	-50	(-208, 109)	2943	(1505, 4381)
Health coverage										
None	2840	(-2385, 8066)	-343	(-585, -101)	1,102	(-453, 2658)	-129	(-578, 320)	678	(-4082, 5437
Medicaid	3707	(1084, 6331)	349	(154, 545)	843	(204, 1482)	180	(-58, 418)	6042	(3098, 8986)
Private	315	(-2082, 2713)	-185	(-384, 14)	<b>-4</b> 5	(-672, 583)	-113	(-360, 135)	-1222	(-3417, 973)
Cardiometabolic conditions										
Hypertension	-432	(-2244, 1380)	-164	(-336, 8)	670	(261, 1080)	727	(586, 869)	1121	(-508, 2750)
Diabetes	1137	(-225, 2499)	199	(77, 320)	1,380	(1001, 1760)	779	(625, 933)	3823	(2405, 5240)
CVD	3195	(1789, 4601)	396	(273, 520)	1,120	(729, 1510)	560	(405, 715)	5156	(3785, 6528)
Renal	3341	(1547, 5135)	176	(13, 339)	846	(328, 1365)	206	(7, 404)	4782	(2718, 6845)
Amputation	2630	(-4187, 9447)	165	(-216, 545)	334	(-1057, 1726)	-220	(-682, 242)	2786	(-3318, 8891
Behavioral health conditions										
Mental health disorders	873	(-555, 2300)	402	(242, 562)	1,187	(712, 1662)	403	(215, 591)	2467	(750, 4183)
Alcohol/drug use disorders	595	(-1605, 2794)	667	(202, 1131)	477	(-454, 1409)	200	(-172, 571)	1552	(-1948, 5052
Tobacco use disorders	-1514	(-3538, 510)	-138	(-350, 73)	-564	(-1255, 128)	204	(-160, 568)	-1926	(-4518, 665)
Other conditions										
Liver disease	6247	(1892, 10603)	367	(81, 653)	1,068	(44, 2092)	126	(-225, 477)	7885	(2831, 12940)
Malignant cancer	1321	(-856, 3499)	152	(-79, 384)	1,029	(235, 1823)	354	(47, 662)	3683	(558, 6807)

Abbreviations: CI, confidence interval; CVD, cardiovascular disease; ED, hospital emergency department.

cost, describes the influence on costs associated with the measure of health coverage or health status. Unless otherwise noted, adjusted costs were estimated using a generalized linear model with a gamma distribution and a log link function.

†Due to a high percentage of adults with zero costs, the mean adjusted cost difference was estimated using a two-part model. The first part used a logit model to estimate the probability of an individual having non-zero costs and a GLM model with a log link function and gamma distribution for positive costs. The CIs for the mean differences between adults with and without dementia were estimated via bootstrapping using 1000 simulations.

Note: Bolded estimates and 95% CIs are significant because zero is not included with the 95% CI.

<sup>\*</sup>The differences in adjusted treatment costs were estimated from Model 4, the fully adjusted model, that included health coverage and all health status measures. The estimated difference, or average marginal