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The Effect of Medicaid Expansion on Caregiver's Quality of Life

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ABSTRACT

Medicaid expansion has been shown to improve access to care, health, and finances in general populations. Until now no studies have considered how Medicaid expansion may affect informal family caregivers who are the backbone of the long term supports and services infrastructure. Family caregivers provide substantial cost savings to Medicare and Medicaid. Yet, they sustain financial, physical, and mental health strain from their caregiving role which Medicaid expansion may offset. This study evaluated the impact of Medicaid expansion on caregivers' mental health using 2015–2018 data from the Behavioral Risk Factor Surveillance System. After adjusting for demographics, socioeconomic status, and health behaviors, caregivers in Medicaid expansion states had a significantly fewer number of poor mental health days in the previous month than caregivers in non-expansion states ($\beta = -0.528$, CI -1.019 , -0.036 , $p < .01$). Study findings indicate that Medicaid expansion state status was protective for caregiver's mental health.

KEYWORDS

Caregivers; medicaid expansion; state-level policy; social determinants of health

Introduction

Informal caregivers are a critical resource to manage the health care needs of those with chronic disease and/or disability. Informal caregivers offer substantial unpaid labor in the form of in home assistance with tasks such as assistance getting out of bed, dressing, preparing meals, and managing medications (Ornstein, Wolff, Bollens-Lund, Rahman, & Kelley, 2019). This day to day support reduces unnecessary hospitalizations and broader health care utilization (Covinsky et al., 2001). The presence of an informal caregiver also increases community tenure for the care recipient and extends the time before an individual may require nursing home or rehabilitative care, driving down the utilization of long terms care. Collectively, caregivers' actions reduce physical health care costs and the cost of long-term care, the responsibility of which often falls to the public sector (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Chari, Engberg, Ray, & Mehrotra, 2015; Dunbar et al., 2018; National Alliance for Caregiving, 2015; Ornstein, Kelley, Bollens-Lund, & Wolff, 2017; Rabarison et al., 2018). Family caregivers fill critical gaps in our medical and social service systems, without which such systems might become quickly overwhelmed. Yet little attention has been given to their overall health and well-being.

Caregivers, and caregiving, is particularly relevant in this historical moment where demographic shifts are converging with medical advancement to increase the number of individuals needing caregiver support. By 2030 one in every five people in the United States will be retirement age (U.S. Census Bureau, 2018), and soon after older people are projected to outnumber children for the first time in US history. In addition, racial/ethnic minority elders are expected to outnumber non-Hispanic white elders during this same time period (Dilworth-Anderson, Williams, & Gibson, 2002). Given our understanding of racial/ethnic differences in quality of care, it is important for health care systems to

consider the needs of this population and ways in which it can support their family caregivers (Covinsky et al., 2001; Dilworth-Anderson et al., 2002; Han, Nguyen, Drope, & Jemal, 2015).

Older adults often require support with the daily tasks of life as they experience physical decline. Others may experience the symptoms associated with Alzheimer's or other types of dementia, requiring specialized support with daily activities. The estimated cost of this care is 159–215 billion dollars per year in the United States (Friedman, Shih, Langa, & Hurd, 2015). In addition, as Gruenberg (1977) so well predicted, we are facing the “failures of success” as medical technologies increase the life expectancy of individuals with chronic disease and/or disabilities. This increased life expectancy results in a higher number of individuals living with chronic illness and/or disabilities at any given time, as well as an extension of the period for which those individuals may require caregiver support. These two phenomenon, an increase in the old-age dependency ratio as well as the increased number of, and life expectancy for, individuals experiencing chronic illness are colliding to place unprecedented pressure on informal caregivers.

In order for caregivers to be effective, they themselves must be in good enough health to manage the needs of the care recipient. This is no small feat given the documented impacts of caregiving responsibilities (Ornstein et al., 2017; Wolff, Spillman, Freedman, & Kasper, 2016). Caregiving can be physically and psychologically burdensome. Additionally, the trajectory of chronic disease, as well as the emotional state of the care recipient, can often be unpredictable making the work environment and related tasks unpredictable. The literature so well documents the challenges of caregiving that Schulz and Sherwood (2008, p. 105) assert that it “has all of the features of a chronic stress experience” including both physical and psychological strain over time. Pearson's caregiver stress model posits that a variety of factors impact the burden that caregivers face. These factors include individual level characteristics like socioeconomic status (SES), the activities of caregiving itself in terms of duration and intensity, and the role strains experienced as a result of caregiving. A review of the caregiving literature highlights that the results of this stress include “psychological distress, impaired health habits, physiological responses, psychiatric illnesses, physical illness and even death (Schulz and Sherwood, p.106)”. However, Pearson's model also highlights the possibility of mediators between caregiver stress burden and negative health outcomes, which this paper further explores.

Given the ways in which informal caregiving supports our health and social services, the predicted strains these systems will face over the next several decades, and the documented burden that caregiver stress places on caregivers, it is critical that we explore mediators that can reduce the health impacts of such strain in order to maintain sustainability. States have the power to interpret and implement federal policies in ways that substantially improve the health and well-being of its residents or in ways that may cause harm; this is especially true for their most vulnerable residents (Rosenbaum, Schumucker, Rothenberg, Gunsalus, & Beckerman, 2017). The Affordable Care Act (Act, 2010) expanded health coverage for residents in all states, but the supreme court decision of 2012 (“National Federation of Independent Business v. Sebelius,” 2012) made the decision to expand Medicaid benefits to a wider range of low-income individuals optional, allowing states to opt in or out of Medicaid expansion. As of November 2019, 37 states, including the District of Columbia, chose to expand Medicaid benefits and 14 states opted against expansion (Kaiser Family Foundation, 2019). Research on Medicaid expansion demonstrates a wide range of positive impacts, these include increasing access to quality care, lowering hospital readmission rates, increased financial security, and reduced eviction rates to name a few (Allen et al., 2019; Courtemanche, Marton, Ukert, Yelowitz, & Zapata, 2017; Han et al., 2015; Sommers, Maylone, Blendon, Orav, & Epstein, 2017; Wen, Johnston, Allen, & Waters, 2019). Study results highlighting the financial impacts of Medicaid expansion stand out as examples of health care policies having an impact outside of the health care system itself. They also highlight the vulnerability of the Medicaid population to policy shifts.

Caregivers are largely absent from analyzes of the impact of Medicaid expansion, despite the likelihood that they are both direct and indirect targets of expansion. Our analysis examines whether and how Medicaid expansion impacts caregiver well-being. The results provide important insights to

providers, payers, and policy makers in expansion and non-expansion states as well as in the federal government.

Methods

Using data from the Behavioral Risk Factor Surveillance Survey (BRFSS) collected in 2015–2018, we investigated the impact of Medicaid expansion on caregivers. The BRFSS is an annual telephone survey of non-institutionalized adults 18 years of age or older living in the United States implemented by each state's department of health. In 2015 states were offered an updated version of the optional caregiver module. This update consisted of 9 items about informal caregiving, including the reason for caregiving, relationship to care recipient, caregiving type, caregiving intensity and duration of care, as well as unmet caregiver needs.

Of the 44 states that included the BRFSS caregiving module at least once between 2015–2018, 22 states completed the caregiver module after expanding Medicaid benefits, 14 states did not expand Medicaid benefits, and the 8 states that included the caregiving module *before* expanding Medicaid benefits were excluded from the analysis. In states that collected caregiving data for more than one year, this data was collapsed into our overall sample. Of the 36 states in the analysis, 9 states administered the caregiver module for multiple years. The analysis adjusted for overrepresentation by dividing the CDC survey weights by the number of years the state had caregiver module data. Because our analysis used only publicly available data, this study was exempt from Institutional Review Board review.

Measures

We classified our main independent variables – caregiving status and Medicaid expansion state residence – in two binary variables. BRFSS respondents who self-reported they provided regular care or assistance to a friend or family member who had a health problem or disability within the previous 12 months were considered caregivers; those who responded they had not provided such care were considered non-caregivers. We also classified whether caregivers and non-caregivers resided, or did not reside, in a Medicaid expansion state. We based this definition of the timing of the expansion status from the Kaiser Family Foundation materials (Kaiser Family Foundation, 2019).

For the regression models, our dependent variable was mental health quality of life (MHQOL). MHQOL days was determined based on response to the following question, “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?”. Thus, the units of this measure were in days, and more days reflected lower mental health quality of life. These questions are widely used as a population health measure (Jia, 2004; Moriarty, Zack, & Kobau, 2003), with good psychometric properties (Andresen, 2003) including construct and predictive validity (Barile et al., 2016).

The BRFSS also collected demographic, socioeconomic, health care, and health status information, all by self-report. The demographic information included was: age group (18–26, 27–49, 50–64, 65+); race/ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic other, Hispanic); gender (male, female, please note the BRFSS did not offer an option for transgender or non-binary); and marital status (married/coupled, not married/not coupled). Socioeconomic variables included highest level of education attained (less than college degree, college degree or higher); employment status (employed, homemaker, self-employed, student, out of work, retired, unable to work); Veteran status; children in household; and income category (less than 20,000, USD 20,000 USD–\$34,999, 35,000 USD–\$74,999, 75,000 USD or more). Health behaviors included leisure time physical activities, body mass index score categories (obese/not obese), meeting criteria for heavy drinking, and current smoker status. The analysis also included three-way interaction terms assessing the impact of caregiver status, Medicaid expansion state status and respondent race/ethnicity.

Analysis plan

We generated descriptive statistics (means and frequencies) of respondent demographic characteristics, socioeconomic status, health care use, health behaviors, and caregiving behaviors for both groups, caregivers in expansion and non expansion states. To understand between group differences, we employed one way ANOVA and chi-square test.

Finally, we fit linear regression models predicting respondents' days of poor MHQOL in the preceding month as a continuous dependent variable. Model 0 was the unadjusted relationship of caregiving, expansion state residence, and the interaction between the two to capture the marginal difference in caregivers' MHQOL days by expansion status. Sets of possible confounding variables were included sequentially: Model 1 added the demographic variables (age group, gender, race, and marital status), Model 2 added to Model 1 with socioeconomic variables (education level, employment status, if children in the home, and income category); and Model 3 added health behaviors (time for leisure activities, obesity status, heavy drinking status, and if current smoker).

BRFSS used a complex sampling approach to sample individuals, which we accounted for by using the Taylor series linearization method to adjust the regression model standard errors. Similarly, we applied the BRFSS sampling weights that result in population representative estimates of each state. Analysis was completed using R, and statistical code to replicate the results is available from the authors upon request.

Results

The weighted BRFSS sample represented approximately 158.7 million individuals, roughly 20% of the sample in expansion and non-expansion states each were caregiving. Non-expansion state caregivers had significantly higher prevalence of having 14 or more poor mental health days in the past 30 days (14.8% vs. 12.4%, $p = .001$) than their expansion state counterparts.

Table 1 provides descriptive statistics for the full BRFSS sample, providing demographic information as well as data on health behaviors stratified by caregiver status and Medicaid expansion state status. The table documents significant differences by age, race/ethnicity, education, employment status, the presence of children in the home, and income category, all at the $p = <0.001$ level. The caregiver-only sample had a higher proportion of females than the full sample. The income gap between individuals in expansion and non-expansion states was narrower in the non-caregiver sample than in the caregiver-only sample. In terms of the health behaviors of caregivers in expansion and non-expansion states, significant differences at the $p = <0.001$ level were observed in number of poor mental health days, participation in leisure time physical activities, BMI category, and current smoker status.

We found significant differences in the number of hours per week spent on caregiving tasks ($p = <0.001$), main health problem or disability the caregiver is addressing ($p = .002$), and type of care provided ($p = .003$) between caregivers in expansion and non-expansion states (**Table 2**). In terms of main health problem or care need, compared to their non-expansion state counterparts, expansion state caregivers were more likely to be providing care for dementia, old age, or cancer. Non-expansion state caregivers were more likely to be providing care for chronic diseases or for care needs that fell into the "other" category.

Table 3 presents the findings from the regression models predicting the number of poor mental health days over 30 days (see supplement for detailed model). The reference group in the intercept is non-Caregivers in non-expansion states. Across all models, we found that being a caregiver significantly increased the number of poor mental health days per month, with the regression coefficients ranging from 1.367 ($p < .01$, CI 0.928,1.827) in the unadjusted model to 1.023 ($p = <0.01$, CI 0.603,1.444) in Model 3. Being a caregiver in an expansion state was protective in all of the models (Model 0 = -0.743 , $p < .01$; Model 1 = -0.671 , $p < .001$; Model 2 = -0.530 , $p < .05$; and Model 3 = -0.528 , $p < .01$).

Table 1. Characteristics of caregivers and non-caregivers by expansion state status: behavioral risk factor surveillance system (Weighted Sample*), 2015–2018.

	Caregivers		Non-Caregivers		<i>p</i>
	Expansion	Non-Expansion	Expansion	Non-Expansion	
Unweighted n	36,370	16,938	138,190	60,516	
Weighted n	19,547,437	13,276,399	79,197,890	46,758,449	
	%	%	%	%	
Age					<0.001
18–26	9.1	10.8	10.3	11.7	
27–49	29.7	34.0	31.0	34.4	
50–64	33.4	30.1	29.8	27.1	
65+	27.9	25.1	28.9	26.8	
Female	56.0	55.2	54.4	53.5	0.137
Race/Ethnicity					<0.001
Non-Hispanic White	68.2	66.1	67.9	66.6	
Non-Hispanic Black	9.3	15.7	7.9	13.1	
Non-Hispanic, Other	7.9	4.9	7.8	4.1	
Hispanic	12.8	12.0	14.8	14.7	
DK/Refused	1.8	1.2	1.7	1.5	
Not married/Not coupled	44.9	45.1	45.3	44.2	0.559
Less than college education	63.8	76.5	63.2	71.6	<0.001
Employment status					<0.001
Employed for wages	42.8	41.4	43.5	44.7	
Homemaker	5.9	6.9	6.2	6.4	
Self-employed	9.4	10.8	9.2	9.1	
Student	3.8	3.9	4.1	4.0	
Out of work	5.3	6.9	4.9	4.2	
Retired	25.5	21.0	25.6	23.6	
Unable to work	7.3	9.1	6.5	8.1	
Veteran	11.3	12.1	10.4	12.1	0.003
Children in household (%)	29.2	34.0	30.6	33.1	<0.001
Income (%)					<0.001
<\$20,000	14.8	18.2	15.1	16.3	
\$20,000–34,999	15.6	20.7	15.2	17.9	
\$35,000–74,999	25.1	26.1	23.8	26.6	
\$75,000+	30.5	22.5	31.9	25.7	
Missing	14.0	12.6	13.9	13.4	
14 or more poor MHQOL days	12.4	14.8	10.1	10.3	<0.001
Participate in leisure time physical activities					<0.001
Yes	75.4	73.0	75.2	72.0	
No	23.7	26.5	23.9	27.3	
Missing	0.9	0.5	1.0	0.7	
BMI category					<0.001
Obese	30.0	33.2	26.9	30.2	
Not Obese	64.0	61.9	66.5	63.7	
Missing	6.0	4.9	6.6	6.1	
Heavy drinker					0.013
Yes	5.3	6.7	5.6	5.8	
No	90.7	90.2	89.7	90.4	
Missing	4.0	3.1	4.7	3.8	
Current smoker	16.4	20.9	13.7	16.2	<0.001

Figure 1 illustrates the Table 3 results, showing the predicted number of days of poor mental health by caregiving and expansion state status with each panel reflecting the different regression models ranging from the unadjusted model on the left to the fully adjusted model on the right (see Supplemental materials for detailed regression model output). Within each of the panels, the difference between caregivers and non-caregivers varies by expansion state status. Throughout, the results show that the gap between caregivers and non-caregivers MHQOL is more pronounced in non-expansion states than in expansion states. Although the number of the predicted days of poor mental

Table 2. Caregiving relationship and caregiver behaviors by expansion state status: BRFSS data 2015–2018 (weighted).

	Expansion	Non-Expansion	
Unweighted n	36,370	16,938	
Weighted n	19,547,437	13,276,399	
	%	%	<i>p</i>
Relationship between caregiver and care recipient			0.892
Child	8.8	8.6	
Parent/Parent-in-law	36.8	38.4	
Grandparent	8.3	7.4	
Sibling	8.1	8.1	
Spouse/Partner	14.9	14.7	
Other Fam	8.0	8.2	
Non-Fam	15.1	14.7	
Average hours of caregiving provided per week			<0.001
Less than 8 hours	56.2	55.7	
9–19 hours	16.3	12.2	
20–39 hours	9.6	11.2	
40+ hours	17.9	20.9	
Length of time providing care			0.230
Less than 1 month	18.8	19.4	
1–6 months	13.3	11.8	
7 months–2 years	18.5	18	
2–5 years	20.3	19.1	
5+ years	29.1	31.7	
Main health problem of care recipient			0.002
Cancer	9.8	8.3	
Chronic Disease	28.3	30.6	
Dementia	10.7	8.9	
Developmental disability	4.9	3.6	
HIV	0.5	0.2	
Mental Illness/Substance Use	7.0	6.0	
Old Age	7.8	6.9	
Other	31	35.5	
Type of care provided in past 30 days			0.003
Household only	32	29.8	
Personal only	5.5	6.0	
Both	47.2	51.6	
Neither	15.4	12.6	
Type of support most needed, but not received			0.398
Individual Counseling	3.7	2.6	
Support Groups	2.6	2.7	
Education about giving care	1.9	2.3	
Respite Care	2.6	2.3	
Service Referrals	9.1	8.9	
None	80.2	81.2	

Table 3. Regression models predicting the number of poor mental health quality of life days in the previous 30 days (Beta Coefficient and 95% confidence intervals).

	Model 0 Unadjusted	Model 1 Demographics	Model 2 Model 1 + SES	Model 3 Model 2 + Health Behaviors
Expansion	−0.057 (−0.282, 0.168)	−0.066 (−0.286, 0.154)	0.102 (−0.116, 0.320)	0.173 (−0.040, 0.386)
Caregiver	1.367*** (0.928, 1.807)	1.252*** (0.829, 1.675)	1.094*** (0.672, 1.515)	1.023*** (0.603, 1.444)
Expansion x Caregiver	−0.743*** (−1.261, −0.224)	−0.671*** (−1.170, −0.171)	−0.530** (−1.026, −0.034)	−0.528** (−1.019, −0.036)
Intercept	3.523*** (3.336, 3.710)	2.829*** (2.429, 3.229)	1.484*** (1.040, 1.928)	0.727*** (0.296, 1.158)
Observations	252,014	252,014	252,014	252,014

p* < 0.1; *p* < 0.05; ****p* < 0.01

The reference group in the Intercept is Non-Caregivers in Non-Expansion States.

SOURCE: Behavioral Risk Factor Surveillance System, 2015–2018

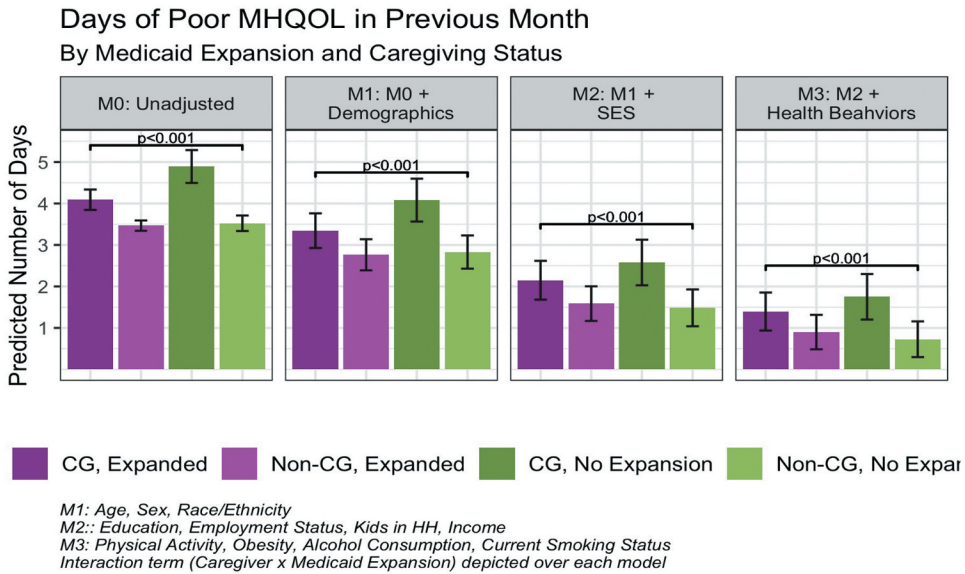


Figure 1. Predicting days of poor mental health quality of life in the previous month by Medicaid expansion and caregiver status. SOURCE: Behavioral Risk Factor Surveillance System, 2015–2018

health decreases as more covariates are included in the models, the patterns observed highlight the difference between Medicaid expansion and non-expansion states.

Discussion

Results from the regression models indicate that caregivers fare worse in terms of mental health quality of life (MHQOL) than non-caregivers across both Medicaid expansion and non-expansion states, this is consistent with the prior literature on the negative impacts of caregiving (Adelman et al., 2014; National Alliance for Caregiving, 2015; Ornstein et al., 2017). However, when comparing MHQOL of caregivers in expansion states to that of caregivers in non-expansion states we found that caregivers living in Medicaid expansion states were predicted to have fewer poor mental health days than caregivers living in non-expansion states. This finding suggests that Medicaid expansion is a protective factor for caregivers' mental health. The magnitude of this effect results in placing caregiver's MHQOL in expansion states on par with that of non-caregivers in either expansion or non-expansion states.

These results should be considered in light of their limitations, including that the cross-sectional nature of the data renders the inability to follow individual caregivers over time as Medicaid expansion rolled out. In addition, we were not able to take into consideration state-level variation in how states designed or implemented the expansion of their Medicaid programs. Our difference-in-difference analytic approach is a commonly used framework for this sort of question; however, it is not without valid critiques (Daw & Hatfield, 2018) for health policy research. These design limitations notwithstanding, our analysis has many strengths, including the variety of demographic and socioeconomic variables that were adjusted for in this analysis and the use of a population health relevant measure of mental health burden from caregiving. In addition, this data makes use of a rare combination of state level data with data on caregivers to generate novel evidence about the impact of Medicaid expansion on an extremely important but understudied group: informal, unpaid caregivers.

The social determinants of health framework helps us consider the interplay between environmental context and an individual's social health and behavioral health, suggesting that health outcomes can be

altered by an individual's "socioeconomic status, education, neighborhood, physical environment, employment, social supports and access to health care" (Artiga, Hinton, & Foundation, 2019). Previous research explored demographic differences between Medicaid expansion and non expansion state populations, which by themselves could drive differences in health care outcomes (Han et al., 2015; Rosenbaum et al., 2017). One of the strengths of this analysis is our ability to control for many of these factors as covariates in our regression models, which better isolates the impact of the policy itself.

There are seismic demographic shifts happening in the age distribution of the population in the United States. Aging baby boomers will place substantial burdens on both our health and behavioral health care systems as well as on their informal caregivers (Knickman & Snell, 2002). This phenomenon is compounded by the "failures of success" in the medical system (Gruenberg, 1977), new treatments for chronic diseases that extend the life of patients and therefore the duration of their need for caregiver support. The combination of the shifting demographic and longer life expectancy for those with chronic disease places a burden on both the structure of the health care system to meet those needs, and the cost it will take to do so. Experts are concerned about not only the cost of care, but the overflow impact those costs will have on other areas of the federal budget (Lee & Skinner, 1999). Aging baby boomers may bring our health care system to a crisis point.

One way to reduce the cost of health care, while at the same time expanding the ability to provide care, is to focus on informal caregivers. As discussed earlier, informal caregivers both extend the capacity of formal health services and reduce the cost of acute and long term care. However, as we also discuss, there are health and behavioral health consequences borne by the caregiver, which could, in essence, represent cost-shifting from the recipient of care to the caregiver, especially in the case where both parties receive health care through the same payer, for instance Medicaid. In order to truly save costs, one would have to moderate the burden on caregivers. Our analysis shows that Medicaid expansion may do just that. In fact, our regression models predict that Medicaid expansion may equalize the mental health quality of life between caregivers and *non* caregivers—quite a stunning finding. Thus Medicaid expansion may have a role in reducing the global cost of health care as the population ages by mediating the impact on informal caregivers, in essence, reducing or eliminating the cost shifting described above.

At the local level, the implications of these findings on provider organizations and payers of care, regardless of Medicaid expansion state status, are significant. Caregivers should be viewed as a critical member of the recipients treatment team. As such, both groups should consider developing or augmenting programming tailored to identifying and addressing the needs of caregivers who are often overlooked given our focus on the recipient of their care. Doing so could lead to reduced healthcare cost, increased efficiency within the system, and improvements in quality of care. While no programs like this exist currently to our knowledge, evidence-based models that include caregivers in the treatment team should be piloted, tested, and expanded.

Given the potential impacts of the aging demographic and the increased life expectancy of those with chronic diseases, good data about caregivers is critical to both anticipating and managing caregiver impacts. This analysis suggests that BRFSS data can be used successfully to study the impact of a "natural experiment", like Medicaid expansion. Likewise, it could also be used to understand other policy and practice interventions at the state or federal level when multiple years of data exist. Based on our findings, we recommend that all states include the caregiver module to gain a better understanding of the needs of caregivers within their state, and that the data be collected before and after any major intervention with potential caregiver impacts. Other optional modules in the BRFSS may also be useful to track and measure the impact of policy intervention. States should consider the BRFSS when they undertake any new policy initiative with potential health impacts.

Our results support our hypothesis that the choice to expand Medicaid benefits to low income individuals positively impacted caregivers well-being. The implications are far reaching and deserve serious consideration by both state and federal policy makers.

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