



ELSEVIER

Contents lists available at [ScienceDirect](http://ScienceDirect.com)

Geriatric Nursing

journal homepage: www.gnjournal.com

Feature Article

Caregivers for older adults: Prevalence, characteristics, and health care utilization and expenditures

Shirley Musich, PhD^{a,*}, Shaohung S. Wang, PhD^a, Sandra Kraemer, MSW^b, Kevin Hawkins, PhD^a, Ellen Wicker, MHA^c^a Advanced Analytics, Optum, 315 E. Eisenhower Parkway, Suite 305, Ann Arbor, MI 48108, USA^b UnitedHealth Group Alliances, 9800 Healthcare Lane, Minnetonka, MN 55343, USA^c AARP Services, Inc., 601 E. Street, N.W., Washington, DC, 20049, USA

ARTICLE INFO

Article history:

Received 4 May 2016

Received in revised form

21 June 2016

Accepted 27 June 2016

Available online xxx

Keywords:

Caregiver

Older adults

Health care utilization

Health care expenditures

ABSTRACT

The purpose of this study was to provide an overview of caregiver prevalence and characteristics and to estimate the impact of caregiving on health care utilization and expenditures among AARP® Medicare Supplement insureds to inform caregiver intervention strategies. A subgroup with live-in partners was used to investigate the additional effect of live-in health status on caregiver health. Multivariate regression models were utilized to determine caregivers' characteristics and associated impacts on their health care utilization and expenditures. Among respondents ($n = 18,928$), 14.9% self-identified as caregivers. The strongest characteristics included being younger, healthier, but reporting depression or loneliness. Caregivers of sicker live-ins were female, older and indicated moderate loneliness; caregivers of healthier live-ins were younger, healthier, but reported severe loneliness. Caregivers had significantly lower inpatient admissions and medical and prescription drug expenditures. These results indicated an adverse impact on psychological health associated with caregiving but no evidence of a negative impact on physical health.

© 2016 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

Caregivers are self-identified individuals who provide unpaid or informal care for sick, disabled and/or cognitively impaired older adults, typically family members or friends.^{1,2} Because these individuals provide an important societal benefit in caring for family and/or friends, much interest has been directed to developing intervention strategies to support their efforts. A 2014 nationally representative caregiver report estimated that there are about 18 million caregivers in the US providing informal care for 9 million older adults.^{1,2} The prevalence of caregivers for older adults in the US has been reported to range from about 12% to 19%.^{3–5} Ideally, general caregiver intervention strategies could be developed to provide resources, support systems and to serve the health needs of broad segments of this population. Such strategies imply an understanding of prevalence of relevant caregiver subgroups, their

demographic and socioeconomic characteristics and the impact of caregiving on their personal health.

Caregiving has been associated with perceived physical and mental health burden on the individuals providing care, especially among those caring for persons with multiple conditions or disabilities. Caregiver burden is generally defined as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning and is measured with various self-reported burden scales.^{6,7} Estimates of those with high self-reported burden range from 15% to 32% depending upon the study population and generally is associated with care for those with dementia, Alzheimer's disease, advanced disease (e.g., cancer) or extensive disabilities.^{2,4–8} Risk factors for caregiver burden include lower income, lower education, living with the care recipient, higher number of hours spent caregiving, and self-reported depression, social isolation, financial stress and lack of choice in being a caregiver.^{1,6,8–10} In contrast, sizable percentages (i.e., estimated at 68%)² of caregivers report little or no burden with positive experiences associated with caregiving including enhanced purpose in life, higher life satisfaction and higher quality of life.^{3,4,8–13}

Conflicts of interest: None.

* Corresponding author. Tel.: +1 248 626 0082.

E-mail address: shirley.musich@optum.com (S. Musich).

Caregiver research studies have a long history but often focus on subgroups of caregivers associated with selected diseases or conditions.^{4,7,9,11–19} Most caregiver studies are characterized as cross-sectional, academically based with small study groups (e.g., 90–100) recruited from various caregiver support groups or specialty clinics to meet specific study criteria (e.g., minimum hours of care; spouses only; selected conditions or disabilities). Few longitudinal studies have been conducted.^{15,20,21} Results are generally self-reported on various surveys or in-person interviews; many with no control groups.^{7,9,11–15,17–19} Few randomly selected or representative caregiver studies have been published.^{1,3,4,8,22,23} Consequently, study results are often not generalizable and conclusions can be contradictory depending on the characteristics of the study populations. Thus the scientific research completed to date was not adequate to inform our purpose of identifying a population-level caregiver intervention strategy.

The most consistent evidence across research studies has focused on psychological stress among caregivers, with depression most often measured. Depression rates reported have ranged from 13% to 44%.^{6,8,11,12,17,18,22,24} The evidence for detrimental impacts of caregiving on physical health is less compelling and, if present, generally associated only with high levels of documented burden.^{4,8,12,17,23} Two large meta-analyses concluded slight to no impact on physical health associated with caregiving.^{25,26} In addition, reduced rates of mortality have been associated with caregiving.⁴ Thus, any observed detrimental physical health effects tended to be associated with those providing more hours of care per week (e.g., 60 or more hours)^{1,8,24} or those caring for advanced dementia, Alzheimer's disease or other advanced disease conditions.^{10,21}

Likewise, the impact of caregiver status on self-reported medical utilization is not consistent across studies. Self-reported hospitalizations for caregivers and non-caregivers were not significantly different,^{8,18,21} or, in contrast, caregivers handling *more* problem behaviors for their spouses with Alzheimer's disease were significantly *less* likely to be hospitalized.²¹ Caregivers experiencing high levels of burden self-reported having increased likelihoods of not getting enough rest, not having time to recover from illnesses, not having time to exercise, forgetting to take prescriptions and no time to see their own physicians.^{10,27}

Our interest was to develop an intervention strategy to serve caregiver health needs at the population-level within the Medicare Supplement population. Most (about 90%) of those with original fee-for-service Medicare coverage have some type of supplemental insurance coverage; about 28% (currently about 10.2 million adults) have purchased Medicare Supplement (i.e., Medigap) coverage.²⁸ While updates of caregiver reports are regularly published,^{2,5} we could find no published research studies investigating the prevalence of caregiving and its consequences among older adults with Medigap plans. Furthermore, few studies have utilized randomly selected study populations to document the prevalence of caregivers or detail their characteristics; no studies have used measured health care utilization or expenditure outcomes from administrative data sources to augment self-reported health status or medical utilization (e.g., number of hospitalizations; number of prescription drugs). In the US, the cost-effectiveness of interventions is typically evaluated as a function of cost-savings associated with reduced medical or drug expenditures. Documenting the impact of caregiving on measured health care utilization and expenditures could inform potential return on investment (ROI) calculations associated with different levels of interventions (i.e., low-intensity generic programs vs. personalized high-intensity interventions).

Thus, the primary objective of this study was to estimate the prevalence of caregivers among AARP[®] Medicare Supplement

insureds and determine characteristics associated with caregiver status to inform population-level intervention strategies. An additional objective was to determine the impact of caregiver status on the individual's 1) health care utilization (i.e., inpatient admissions and emergency room visits); and 2) medical and prescription drug expenditures. The potential for cost-savings in medical and/or drug expenditures could thus inform appropriate investment levels directed toward caregiver interventions should return on investment become a priority in decisions to support any given intervention strategy.

In addition, these objectives were considered for a subgroup of survey respondents with live-in partners (i.e., at the same address; with and without caregivers) with AARP Medicare Supplement health plans stratified according to the live-in's health status (sicker vs. healthier as determined from medical diagnosis codes and expenditure levels). This second study population provided an insight into the impact of the health of the care recipient on the mental and physical health of the caregiver.

Methods

Sample selection

In 2015, approximately 4 million Medicare insureds were covered by an AARP Medicare Supplement plan insured by UnitedHealthcare Insurance Company (for New York residents, UnitedHealthcare Insurance Company of New York). These plans are offered in all 50 states, Washington DC and various US territories. From September through December 2015, AARP Medicare Supplement insureds in three states (Missouri, New Jersey and Washington) were randomly surveyed to screen for general health needs. The survey included a single question assessing caregiver status (yes/no). To be eligible for this prospective cross-sectional study, survey respondents were required to be at least 65 years of age, to have answered the caregiver question and to have a minimum of three months of AARP Medicare Supplement plan coverage pre-survey completion. The primary study sample included 18,928 survey respondents and was used to determine overall prevalence, characteristics and the subsequent impact of caregiving on health care utilization and expenditures of the caregiver.

A second study population included the additional criterion of having a live-in AARP Medicare Supplement insured (i.e., living at the same address). This study subgroup included 7849 (42%) of the original sample and was used to stratify caregivers and non-caregivers based on the health status of their live-in person determined from diagnosis codes and health care expenditure levels.

Survey

The general health needs survey (21 questions) was developed and validated in 2014 by UnitedHealthcare to screen insureds for health status (e.g., self-reported health status, number of prescription drugs and number of hospitalizations), physical health risks (e.g., physical inactivity, difficulty with walking/balance and disabilities), mental health risks (e.g., loneliness, depression and lack of social networks or support), health literacy and willingness to participate in provided health programs. Caregivers were identified by answering "yes" to the following screening question: Do you provide care for or look after a person who is ill, frail or disabled? The survey was delivered via Interactive Voice Recognition (IVR) telephonic out-bound calls from a designated list of 100,000 randomly selected insureds.

Outcomes

Health care utilization and expenditures

Health care utilization was defined from administrative medical claims as an inpatient admission or emergency room visit within one-year pre-survey completion. Health care expenditures (per member per month; pmpm) were defined as paid claims from the same time period aggregated from Medicare, Medicare Supplement and patient out-of-pocket paid amounts. Prescription drug expenditures (pmpm) included AARP Medicare Rx paid claims and patient copayments for those also enrolled in an AARP Medicare Part D prescription drug plan ($N = 10,322$ (55%) of the overall sample; $N = 4240$ (54%) of the sample with live-ins).

Covariates

Covariates were included to characterize caregivers and to adjust for factors that may influence health care utilization and expenditures. These covariates included measures of demographics, socioeconomic factors, health status and other characteristics taken from health plan eligibility and administrative medical claims.

Demographics

Demographic questions included age and gender. Age groups were defined as: 64–69; 70–79; ≥ 80 years. Living in urban and other locations; low, middle or high income areas; and high, medium or low minority areas were geocoded from zip codes. AARP Medicare Supplement plan types were grouped by cost-sharing levels, including high-level coverage plans with no copayments or deductibles (plans C, F and J), medium-level coverage (plans B, D, E, G, H, I and N) and low-level coverage (plans A, K and L).

Loneliness, depression and health literacy

Loneliness was measured using the validated University of California-Los Angeles (UCLA) three-item scale with responses never/hardly ever, some of the time and often.²⁹ The questions were scored 1 to 3 then summed to a score ranging from 3 to 9. Loneliness was subsequently categorized as: no loneliness (score = 3); moderate loneliness (score = 4 or 5); and severe loneliness (score = 6–9).

The validated two-item depression questionnaire, Patient Health Questionnaire-2 (PHQ-2), was used to screen for depression.³⁰ Scores of 3 or higher on the PHQ-2 are generally accepted as required to indicate follow-up for more precise depression diagnosis.

Health literacy was measured with the single validated question asking for confidence level in filling out medical forms.³¹

Self-reported number of prescription drugs

The number of prescription drugs taken by the individual was self-reported on the survey as a continuous variable: how many different prescription drugs do you take each day? The number of prescription drugs was subsequently categorized as: 0 prescription drugs; 1–3 prescription drugs; 4–6 prescription drugs; or 7 or more prescription drugs.

Other covariates

Self-reported perception of one's personal health was determined by asking respondents to compare their health to others in

their age group with the following categories: much better, slightly better or about the same/worse. Physical activity was assessed from a single survey question querying number of days per week the respondent engaged in at least 30 min or more of light-to-moderate physical activity categorized as: no physical activity 0 days; low 1–2 days; and high 3 or more days. Willingness to participate in programs to enhance one's health (yes/no) was used as a marker to indicate engagement in caring for one's own health. The need to spend most of one's time in the house (yes/no), needing help because of one's health (yes/no) and finding it hard to get needed help especially on daily tasks (yes/no) were utilized as indicators of functional status. The extent of social support was determined from a single question querying how often the respondent could count on family or friend support: often, some of the time or hardly ever/never. Social networks were assessed as a count of family or friends that could be counted on for support: 0, 1–2, 3–4 or 5 or more. The demographic, socioeconomic and health status covariates considered are listed in [Table 1](#).

Live-in insured stratified on health status

Survey respondents with live-in insureds (i.e., living at the same address) were identified from plan eligibility information including addresses for survey respondents and their live-in insured. Similarly, the live-ins must have had a minimum of three months of AARP Medicare Supplement eligibility. In lieu of survey results (only one person in a household could complete the IVR survey), health status for live-ins living with a self-reported caregiver or non-caregiver was defined from Charlson Comorbidity Index (CCI) scores.³² The CCI is a measure of the risk of one-year all-cause mortality attributable to selected comorbidities (identified from diagnosis codes) that has also been shown to be highly predictive of morbidity and health care expenditures.

Using the distribution of CCI scores, those live-ins with a CCI score of 3 or higher were categorized as "sicker" and those with a CCI score of 2 or less as "healthier." This cut-point provided a 40/60 split of the live-ins: a distribution providing a suitable sample size for evaluation and similar to the estimated 30% of caregivers likely to demonstrate a negative impact on their health when the care recipient is sicker and requires more intensive care. The demographics and health conditions associated with the CCI scoring for four subgroups are documented in [Table 2](#): caregivers with live-in sicker ($N = 601$); caregivers with live-in healthier ($N = 927$); non-caregivers with live-in sicker ($N = 1459$); and non-caregivers with live-in healthier ($N = 4872$). Caregivers with live-in sicker insureds were compared to caregivers with live-in healthier insureds to assess the impact of the health status of the care recipient on caregiver mental or physical health. Caregivers with healthier live-ins were compared to non-caregivers with healthier live-ins to assess the impact of caregiving status on their mental and physical health holding the health status of the live-in constant at healthier. No further analyses were conducted on the non-caregivers with sicker live-ins subgroup.

Statistical models

Propensity weighting for survey non-response bias

Propensity weighting was used to adjust for potential selection bias often associated with survey response to enhance the generalizability of these findings. The propensity weighting utilized available information about the demographic, socioeconomic and health status variables described above that could potentially influence survey response. This information was used to estimate the underlying probability of survey response for each individual. We

Table 1
Unadjusted demographic characteristics of caregivers and non-caregivers.

	All % or mean	Caregiver % or mean	Non-caregiver % or mean	p-value	With live-ins % or mean	Caregiver % or mean	Non-caregiver % or mean	p-value
Number	18,928	14.9	85.1		7859	19.4	80.6	
Gender								
Male	33.4	33.0	33.5	0.60	33.0	30.4	33.7	0.02
Female	66.6	67.0	66.5		67.0	69.6	66.3	
Age	74.9	73.9	75.0	<0.0001	74.0	74.4	73.9	0.008
65–69	30.2	34.1	29.5	<0.0001	29.6	28.7	29.9	0.02
70–79	43.5	45.0	43.2		50.9	49.3	51.3	
80 or higher	26.3	20.8	27.3		19.4	22.0	18.8	
Minority status (geocoded)								
Low	57.6	57.4	57.6	0.17	59.4	58.7	59.6	0.77
Medium	39.1	38.7	39.2		38.2	38.6	38.1	
High	2.6	2.9	2.6		1.7	2.0	1.7	
Medium income (geocoded)								
Low	11.7	12.6	11.5	0.04	10.4	11.7	10.0	0.21
Medium	35.4	36.6	35.2		34.8	35.1	34.8	
High	52.8	50.6	53.2		54.7	53.0	55.1	
Self-rated physical health								
Much better	38.3	42.3	37.6	<0.0001	38.3	41.1	37.7	0.08
Slightly better	23.8	23.3	23.9		24.2	23.6	24.3	
About the same	26.5	23.7	27.0		26.7	25.4	27.0	
Slightly worse	8.2	8.2	8.2		8.0	7.9	8.0	
Much worse	2.0	1.7	2.0		1.9	1.2	2.1	
Physical activity days/week								
0	10.0	8.8	10.2	0.08	9.2	9.6	9.1	0.27
1–2 days	16.7	16.2	16.8		16.7	16.2	16.8	
3 or more days	70.1	71.9	69.8		71.9	71.4	72.0	
UCLA-3 Loneliness Scale								
3 (never/hardly ever)	68.7	68.6	68.8	0.08	78.9	72.3	80.5	<0.0001
4–5 (moderate)	21.1	20.0	21.3		14.6	18.0	13.8	
6 or higher (severe)	9.3	10.5	9.2		5.9	9.0	5.1	
Family social support								
Often	75.7	72.0	76.4	<0.0001	77.8	72.4	79.1	<0.0001
Some of the time	16.5	19.0	16.1		15.0	19.7	13.9	
Hardly ever	4.9	6.0	4.7		4.5	5.8	4.2	
Never	2.5	2.5	2.5		2.4	2.0	2.4	
Social network (#)								
0	3.1	3.0	3.1	0.004	2.9	2.3	3.0	<0.0001
1–2	14.2	16.2	13.8		11.7	15.6	10.7	
3–4	26.6	26.3	26.6		24.8	26.3	24.5	
5 or more	55.8	53.9	56.1		60.2	55.2	61.4	
Need to stay in the house								
Yes	9.6	11.2	9.4	0.007	8.0	11.2	7.3	<0.0001
No	89.4	87.8	89.7		91.2	88.3	92.0	
Need help due to health								
Yes	11.1	10.6	11.2	0.58	9.7	10.1	9.6	0.81
No	88.0	88.6	87.9		89.5	89.1	89.6	
Hard to get help								
Yes	2.8	4.4	2.6	<0.0001	2.2	3.6	1.8	<0.0001
No	8.3	6.2	8.6		7.5	6.5	7.7	
# of prescription drugs								
0	8.1	9.9	7.8	<0.0001	8.6	9.5	8.3	0.14
1–3	39.0	40.0	38.9		40.9	40.3	41.1	
4–6	36.1	34.4	36.4		35.2	35.7	35.1	
7 or more	14.4	13.0	14.7		13.2	11.8	13.5	
PHQ-2 score								
0	75.2	70.7	76.1	<0.0001	77.5	70.6	79.2	<0.0001
1	10.0	11.6	9.7		9.2	12.0	8.6	
2	6.5	8.1	6.2		5.6	8.6	4.9	
3 or higher	6.5	7.7	6.3		6.1	7.3	5.8	
Participate in health programs								
Yes	35.4	37.4	35.1	0.02	33.5	35.8	32.9	0.09
No	61.2	58.8	61.6		63.2	60.7	63.7	
Confidence filling out forms								
Not at all	3.0	2.8	3.1	0.38	2.3	2.2	2.3	0.20
A little bit	3.4	3.2	3.4		3.0	3.1	3.0	
Somewhat	9.4	8.5	9.5		8.7	7.9	8.9	
Quite	18.7	18.5	18.7		18.8	20.7	18.4	
Extremely	57.8	59.0	57.6		60.0	58.3	60.4	
Administrative medical claims								
Any IP admission (annual)	14.4	11.5	14.9	<0.0001	13.5	11.3	14.1	0.005
Any ER visit (annual)	27.8	27.1	27.9	0.41	26.1	25.7	26.2	0.69

UCLA = University of California-Los Angeles; PHQ-2 = Patient Health Questionnaire-2; IP = inpatient; ER = emergency room; COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure. Missing responses, state of residence, urban/rural locations and health plan types were also included but are not shown for brevity.

Table 2

Unadjusted characteristics of live-in insureds: living with caregivers or non-caregivers.

	Live-in with CG sick % or mean	Live-in with CG healthier % or mean	Live-in with non-CG sick % or mean	Live-in with non-CG healthier % or mean
Gender				
Male	77.5	60.8	73.5	62.8
Female	22.5	39.2	26.5	37.2
Age				
35–64	0.5	1.1	0.5	1.0
65–69	12.0	22.1	13.7	25.5
70–79	45.4	47.1	49.4	53.7
80 plus	42.1	29.7	36.3	19.7
Any IP admission	43.2	9.4	32.3	7.3
Any ER visit	56.2	25.6	42.1	19.5
Health conditions (identified from diagnosis codes)				
Any malignancy	28.7	5.2	39.0	7.2
COPD	46.0	9.6	39.1	9.0
Dementia	17.4	8.7	7.8	1.5
Diabetes with complications	36.6	4.2	28.7	3.2
Heart failure	36.2	6.1	26.5	3.4
Metastatic solid tumor	8.4	0.0	7.9	0.0
Mild liver disease	2.8	0.5	5.6	0.8
Mild or moderate diabetes	19.6	14.5	23.2	12.3
Moderate/severe liver disease	2.0	0.0	1.6	0.0
Myocardial infarction	10.3	1.9	11.2	1.4
Peptic ulcer disease	2.8	0.2	2.7	0.4
Peripheral vascular disease	39.9	9.0	34.1	5.4
Renal disease	41.1	1.7	37.9	2.4
Rheumatologic disease	5.3	2.9	6.3	2.1
Stroke	30.2	8.8	24.2	5.5
Medical expenditures (\$; pmpm)	3259.95	716.14	2486.89	535.14
Rx expenditures (\$; pmpm) ^a	483.31	262.43	411.41	149.19

Subgroup numbers: 601, 927, 1459, and 4872, respectively. All variables are statistically different $p < 0.0001$. CG = caregiver; COPD = chronic obstructive pulmonary disease; pmpm = per member per month.

^a Among those with AARP Part D prescription drug plans.

then used that estimated probability to create and apply a weighting variable to the data, to make those who did respond better resemble all eligible insureds who received the survey. The utility of such propensity weighting models to adjust for external validity threats is described elsewhere.^{33,34}

Characteristics associated with caregivers were determined using multivariate logistic regression models for caregivers versus non-caregivers weighted to adjust for survey non-response. Covariates included all of those variables listed in Table 1. Health care utilization and aggregated annual health care expenditures for caregivers and non-caregivers (overall and subgroups) were determined and regression adjusted for demographic, socioeconomic and survey response variables.

Results

Overall, 20,290 AARP Medicare Supplement insureds in the three states responded to the survey (20.3% response rate). Of these, 18,928 (93.3%) met the eligibility criteria for this study: had three months of AARP Medicare Supplement insurance coverage pre-survey and responded to the caregiver question. Survey respondents were mostly female (66.6%), 70–79 years of age (43.5%), high income (52.8%), white (57.6%) and reported better health than others (38.3%). Among survey respondents, the prevalence of caregivers was 14.9% (Table 1).

Among those 7859 (41.5%) survey respondents with live-in insureds, the prevalence of caregivers was 19.4% (Table 1). Similarly, this subgroup was mostly female (67.0%), 70–79 years of age

Table 3

Characteristics associated with caregivers.

Covariate	Odds ratio	p-value
Hard to get help	2.02	<0.0001
PHQ-2 = 2	1.47	<0.0001
Need to stay in the house	1.43	<0.0001
PHQ-2 = 3	1.30	<0.0001
Health much better	1.27	<0.0001
Some family support	1.23	<0.0001
Low income	1.22	<0.0001
No family support	1.19	<0.0001
Middle income	1.12	<0.0001
Health slightly better	1.11	<0.0001
Physical activity 3+ days/week	1.10	0.004
Physical activity 1–2 days/week	1.09	0.02
Intend to participate in health programs	1.05	0.007
Female	1.05	0.02
Low minority (white)	1.04	0.03
Moderate loneliness	0.94	0.01
Age 70–79	0.90	<0.0001
1–3 prescription drugs	0.86	<0.0001
4–6 prescription drugs	0.82	<0.0001
7+ prescription drugs	0.76	<0.0001
Need help due to health	0.75	<0.0001
Age 80+	0.66	<0.0001

PHQ-2 = Patient Health Questionnaire-2.

(50.9%), high income (54.7%), white (59.4%) and reported better health (38.3%).

Live-ins stratified as sicker (CCI ≥ 3) requiring caregivers were mostly males (77.5%), often with chronic obstructive pulmonary disease (COPD; 46.0%), renal disease (41.1%), diabetes with complications (36.6%) or dementia (17.4%) and experiencing higher medical and prescription drug expenditures compared to the categories considered healthier or those categorized as sick living with non-caregivers (Table 2).

Characteristics associated with caregiving

The strongest characteristic of all caregivers was self-reported difficulty in getting needed help (Table 3). Other characteristics associated with caregivers included being younger (<70 years), reporting depression but better health and taking fewer prescription drugs.

Characteristics of caregivers with sick live-ins and caregivers with healthier live-ins

The strongest characteristics distinguishing caregivers of sicker live-ins (compared to caregivers of healthier live-ins; holding caregiver constant) were being female, older, taking more prescription drugs, suffering from moderate loneliness and less likely to be physically active (Table 4).

The strongest characteristics distinguishing caregivers of healthier live-ins (compared to non-caregivers of healthier live-ins; holding live-in health status constant) were severe loneliness, being older and lower income but reporting better health, being physically active and taking fewer prescription drugs (Table 4).

Impact of caregiver on health care utilization and expenditures

Health care utilization for inpatient admissions were significantly lower for caregivers compared to non-caregivers (2.8 annual percentage points lower; Table 5); subsequently, paid medical and drug expenditures were also significantly lower (\$80 pmpm lower medical expenditures; \$18 lower prescription drug expenditures; Table 6).

Table 4
Characteristics associated with caregivers of live-in sicker; caregivers of live-in healthier.

Covariates	Odds ratio	p-value
Impact of caregiving with sicker live-ins		
Female	2.27	<0.0001
Age 70–79	1.69	<0.0001
Age 80+	1.65	<0.0001
4–6 prescription drugs	1.36	0.0004
7+ prescription drugs	1.36	0.006
Moderate loneliness	1.25	0.001
Some family support	1.24	0.001
High health literacy	1.19	0.007
Intend to participate in health programs	0.77	<0.0001
Physical activity 3+ days/week	0.65	<0.0001
Impact of caregiving with healthier live-ins		
Severe loneliness	1.74	<0.0001
Hard to get help	1.52	0.0005
PHQ-2 = 2	1.49	<0.0001
Low income	1.49	<0.0001
Need to stay in the house	1.46	<0.0001
Some family support	1.31	<0.0001
Health much better	1.29	<0.0001
Moderate loneliness	1.29	<0.0001
Age 80+	1.25	<0.0001
Intend to participate in health programs	1.20	<0.0001
Physical activity 3+ times/week	1.14	0.03
Middle income	1.14	0.001
Age 70–79	0.91	0.01
Need help due to health	0.82	0.007
1–3 prescription drugs	0.80	<0.0001
4–6 prescription drugs	0.80	<0.0001
7+ prescription drugs	0.69	<0.0001

N = 1528 (601 caregivers with live-in sick and 927 caregivers with live-in healthier).

Impact of caregiver subgroups on health care utilization and expenditures

Health care utilization for inpatient admissions and emergency room visits were significantly lower for caregivers with sicker live-ins compared to caregivers with healthier live-ins (Table 5). Caregivers with healthier live-ins had significantly lower inpatient admissions compared to non-caregivers with healthier live-ins (Table 6). Subsequently, holding caregiver status constant, paid medical expenditures were significantly lower for caregivers with sicker live-ins but, as expected from self-reports, with significantly higher prescription drug expenditures compared to caregivers with healthier live-ins (Table 6). Similarly, holding health status of the live-in constant, prescription drug expenditures were significantly lower for caregivers compared to non-caregivers (Table 6).

Table 5
Regression adjusted annual utilization of inpatient admissions and emergency room visits by caregivers and non-caregivers; caregivers and non-caregivers with live-ins.

Annualized utilization measure	%		p-value
	Caregiver (N = 2829)	Non-caregiver (N = 16,099)	
All respondents (N = 18,928)			
Any inpatient admission	12.0	14.8	<0.0001
Any emergency room visit	27.8	27.8	0.97
Respondents with live-in insureds (N = 7859)			
Any inpatient admission	11.3	14.1	<0.0001
Any emergency room visit	25.4	26.3	0.10
Subgroup comparisons stratified on live-in insured's health status			
		Caregiver live-in sicker (N = 601)	Caregiver live-in healthier (N = 927)
Any inpatient admission	10.3	11.8	0.03
Any emergency room visit	22.7	26.8	<0.0001
		Caregiver live-in healthier (N = 927)	Non-caregiver live-in healthier (N = 4872)
Any inpatient admission	11.8	13.6	0.001
Any emergency room visit	26.8	26.0	0.25

Discussion

In our population of AARP Medicare Supplement insureds, 14.9% were categorized as caregivers of older adults; with 19.4% caregivers in the subgroup of those living with AARP Medicare Supplement insureds. This prevalence rate of caregivers for older adults is consistent with published ranges for US caregivers of 12%–19%.^{3–5} Overall, caregivers compared to non-caregivers in this study population were younger, healthier, taking fewer prescription drugs with some depression and/or loneliness and lack of social support.

The 40/60 split of the caregiver population into those with sicker and healthier live-ins approximated the 30% of caregivers that might be expected to experience either mental or physical health impacts associated with increased caregiving responsibilities.^{2,5} Those characterized as sicker living with caregivers had high rates of COPD, renal disease, diabetes with complications, heart failure and dementia and high levels of medical and prescription drug expenditures. Thus, sicker live-ins had a combination of advanced diseases and/or dementia rather than any one specific condition and provided a suitable subgroup to test the impact of advanced illness on caregiver mental or physical health.

The strongest characteristics associated with caregivers were finding it hard to get needed help and having to stay in the house. This is consistent with other studies reporting that a major source of caregiver stress is associated with the number of daily tasks involved in providing care (e.g., getting meals, doing laundry, shopping) and the associated hours required^{1,8,21,22,24} rather than patient behavior problems or medical care per se.^{14,15,21} Low levels of psychological issues among caregivers were demonstrated in an increased likelihood of depression (PHQ-2 = 3 or higher) and moderate or severe loneliness. While there was no evidence of the often reported high levels of depression even among the subgroup of caregivers of sicker live-ins,^{12,13,17,18,20,24} longitudinal studies may be necessary to understand the longer term ramifications of both depression and loneliness on caregiver health.

Overall caregivers and caregiver subgroups associated with sicker or healthier live-ins consistently reported better health compared to others their age. The inconsistent conclusions in the scientific literature regarding whether the health status associated with caregivers is poorer or better results from small study populations recruited to suit selected study designs, often associated with caregivers defined with high burden.^{4,8,12,21–23} Our results are consistent with two large meta-analyses focused on physical health burden of caregivers that concluded that there was minimal to no

Table 6

Regression adjusted medical and prescription drug per member per month expenditures for caregivers and non-caregivers; caregivers and non-caregivers with live-ins.

Medical expenditure measures	\$ (pmpm)		p-value
	Caregivers (N = 2829)	Non-caregivers (N = 16,099)	
All respondents (N = 18,928)			
Medical expenditures	945 ^a	1025 ^a	0.004
Prescription drug expenditures	219 (N = 1522)	237 (N = 8800)	0.03
	Caregivers (N = 1528)	Non-caregivers (N = 6331)	
Respondents with live-in insureds (N = 7859)			
Medical expenditures	919 ^a	997 ^a	0.04
Prescription drug expenditures	223 (N = 855)	226 (N = 3385)	0.77
	Caregiver live-in sicker (N = 601)	Caregiver live-in healthier (N = 927)	
Subgroup comparisons stratified on live-in's health status			
Medical expenditures	768 ^a	988 ^a	0.001
Prescription drug expenditures	234 (N = 361)	186 (N = 494)	0.02
	Caregiver live-in healthier (N = 927)	Non-caregiver live-in healthier (N = 4872)	
Medical expenditures	988 ^a	983 ^a	0.91
Prescription drug expenditures	186 (N = 494)	236 (N = 2569)	0.001

^a With an AARP Medicare Supplement plan and an AARP Part D Prescription drug plan.

detrimental impact on physical health associated with caregiving.^{25,26} Additionally, our results are similar to studies that include larger, more representative caregiver populations supporting a “healthy caregiver” hypothesis.^{3,4,8,9,11–13} Caregivers, even those with some levels of burden, have reported enhanced purpose in life, higher quality of life and, consequently, better health associated with caregiving.^{3,4,8–13}

Demographics were not consistent characteristics of caregivers. In the overall caregiver population, female gender was minimally predictive (OR 1.05; $p = 0.02$) along with younger age groups. However, in the subgroup of caregivers taking care of live-ins, female gender was a stronger characteristic (OR 1.16; $p < 0.0001$) along with being older (data not shown). Thus, the demographics of caregivers apparently depend largely on the study population recruited or defined.^{9,13,22} Socioeconomically, as in other studies, caregivers were more likely to be lower income.^{6,10}

To our knowledge, no caregiver studies have used measured administrative medical and prescription drug claims data to document health care utilization or expenditures. Published studies on these topics are self-reported measures of numbers of hospitalizations or emergency room visits or self-reported numbers of prescription drugs on surveys or from in-person interviews.^{8,18,21} Our study population consistently self-reported better health than others and taking fewer prescription drugs, consistent with the younger age groups of overall caregivers.²⁵ This self-reported information by caregivers was confirmed using both medical utilization (i.e., significantly fewer inpatient admissions) and average medical and prescription drug expenditures (i.e., significantly lower expenditures) compared to non-caregivers. Contrary to the literature, we found no evidence that caregivers did not have time to take care of themselves (e.g., more likely to indicate a willingness to participate in health programs) or did not have time for physical activity (e.g., more likely to self-report 3+ days per week of physical activity).^{10,27}

Thus, overall, caregivers in our population were generally younger, healthier with minimal gender bias. Adverse effects were evident on psychological health but physical health was consistently better for caregivers compared to non-caregivers. Since most caregivers experienced lower health care utilization and expenditures than non-caregivers, designing a cost-effective, high-value intervention strategy would likely involve targeting more intensive interventions only to those most in need. More general lower resource interventions could provide support, especially psychological and emotional support, across the broader segments of the population of caregivers. Promising personalized interventions for

caregivers have included problem-solving therapies,³⁵ physical activity programs^{36,37} and social, home and outside leisure pleasurable activities (psychosocial) interventions.³⁸ Lower resource, less intensive caregiver support programs often use online formats to promote sharing, resource awareness and social support (e.g., Caregiver Resource Workshops). As a more general strategy, physicians have been encouraged to be aware of caregiver physical and mental health issues, to include caregivers in their care recipients' visits and to provide support to caregivers in helping them to understand and learn medical care protocols.^{6,18} Desired outcomes for interventions could include either cost savings or quality of life improvements or both. If cost savings is the goal of caregiver interventions, these results would support only low-level/low resource programs for the majority of the population with selective targeting of more intensive programs to those most in need.

Our study population of caregivers among AARP Medicare Supplement insureds may not generalize to all older adults or other Medicare Supplement beneficiaries. While we did adjust for survey non-response, our response rate at 20% was relatively low and included insureds in only three states. The caregiver question was designed to screen a broad population for those self-identifying as caregivers. The question may have missed caregivers who do not identify with the caregiver role. Only a more in-depth follow-up caregiver survey could provide more detail on the demands of the role. However, the purpose of this study was to demonstrate that caregivers could be identified with a single question providing a population-level overview of caregivers and informing the design of an intervention strategy. In this short survey, we did not have a caregiver burden scale or reported hours spent on caring tasks. This limitation could be addressed in a more in-depth caregiver survey developed subsequent to this study. In lieu of survey results for care recipients, live-in partners were stratified based on diagnosis codes and health care expenditures to examine the additional effect of higher levels of medical care responsibilities among caregivers. More information on care recipients via self-reported surveys would have better defined levels of care received and should be considered in subsequent research. Strengths of the study include a relatively large randomly selected study population uniquely incorporating administrative medical and prescription drug claims data to augment self-reported survey results. As health management strategies for older adults move more toward population-level programming, broader identification methods of selected populations (from surveys or claims data) and effective outreach will become priorities.

Conclusions

Self-identified caregivers comprised 14.9% of the AARP Medicare Supplement study population. Characteristics of overall caregivers included being younger, self-reporting better health, taking fewer prescription drugs, finding it hard to obtain help and suffering from depression or loneliness. Caregivers of sicker live-ins were more likely to be female, older, taking more prescription drugs and reporting loneliness; whereas caregivers of healthier live-ins indicated loneliness but were younger, healthier and taking fewer prescription drugs. Overall, caregivers had lower utilization of inpatient admissions and significantly lower medical and prescription drug expenditures. Our results indicated adverse impacts of psychological health among caregivers compared to non-caregivers but no evidence of an impact of caregiving on physical health across any of the caregiver groups.

References

- Kasper JD, Freedman VA, Spillman BC, et al. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff.* 2015;34:1642–1649.
- U.S. Department of Health and Human Services. *Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving*. Washington, DC. Retrieved December 28, 2015 from: <https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf>; 2014.
- Brown SL, Smith DM, Schulz R, et al. Caregiving behavior is associated with decreased mortality risk. *Psychol Sci.* 2009;20:488–494.
- Roth DL, Haley WE, Hovater M, et al. Family caregivers and all-cause mortality: findings from a population-based propensity-matched analysis. *Am J Epidemiol.* 2013;178:1571–1578.
- Weber-Raley L, Smith E. *Caregiving in the United States: Research Report*. Retrieved February 23, 2016 from: <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>; 2015.
- Adelman RD, Tmanova LL, Delgado D, et al. Caregiver burden: a clinical review. *JAMA.* 2014;311:1052–1059.
- Hsu T, Loscalzo M, Ramani R, et al. Factors associated with high burden in caregivers of older adults with cancer. *Cancer.* 2014;120:2927–2935.
- Buyck JF, Bonnaud S, Boumendil A, et al. Informal caregiving and self-reported mental and physical health: results from the Gazel cohort study. *Am J Public Health.* 2011;101:1971–1979.
- Chappell NL, Dujela C. Caregiving: predicting at-risk status. *Can J Aging.* 2008;27:169–179.
- Schulz R, Newsom J, Mattelmark M, et al. Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Ann Behav Med.* 1997;19:110–116.
- Chow EOW, Ho HCY. The relationship between psychological resources, social resources, and depression: results from older spousal caregivers in Hong Kong. *Aging Ment Health.* 2012;16:1016–1027.
- Fisher GG, Frank MM, Plassman BL, et al. Caring for individuals with dementia and CIND: findings from the Aging, Demographics, and Memory Study. *J Am Geriatr Soc.* 2011;59:488–494.
- Jones SL, Hadjistavropoulos HD, Janzen JA, et al. The relation of pain and caregiver burden in informal older adult caregivers. *Pain Med.* 2011;12:51–58.
- Chen MC, Chen KM, Chu TP. Caregiver burden, health status, and learned resourcefulness of older caregivers. *West J Nurs Res.* 2014 Mar;6:1–14.
- Garlo K, O'Leary JR, Van Ness PH, et al. Caregiver burden in caregivers of older adults with advanced illness. *J Am Geriatr Soc.* 2010;58:2315–2322.
- Goldzweig G, Merims S, Canon R, et al. Informal caregiving to older cancer patients; preliminary research outcomes and implications. *Ann Oncol.* 2013;24:2635–2640.
- Mausbach BT, Chattillion EA, Roepke SK, et al. A comparison of psychosocial outcomes in elderly Alzheimer's caregivers and non-caregivers. *Am J Geriatr Psychiatry.* 2013;21:1–13.
- Schubert CC, Boustani M, Callahan CM, et al. Acute care utilization by dementia caregivers within urban primary care practices. *J Gen Intern Med.* 2008;23:1736–1740.
- Tang F, Jang H, Lingler J, et al. Stressors and caregivers' depression: multiple mediators of self-efficacy, social support and problem-solving. *Soc Work Health Care.* 2015;54:651–668.
- Mausbach BT, Chattillion E, Roepke SK, et al. A longitudinal analysis of the relations between stress, depressive symptoms, leisure satisfaction, and endothelial function in caregivers. *Health Psychol.* 2012;31:433–440.
- Shaw WS, Patterson TL, Semple SJ, et al. Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Ann Behav Med.* 1997;19:101–109.
- Chan A, Malhotra C, Malhotra R, et al. Health impacts of caregiving for older adults with functional limitations: results from the Singapore Survey on Informal Caregiving. *Aging Health.* 2013;25:998–1012.
- Jowey T, McRae I, Gillespie J, et al. Time to care? Health of informal older carers and time spent on health related activities: an Australian survey. *BMC Public Health.* 2013;13:374.
- Wolff JL, Spillman B. Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: prevalence, characteristics, and hours of care. *J Gerontol B Psychol Sci Soc Sci.* 2014;69 suppl 1: S65–S72.
- Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci.* 2007;62B:P126–P137.
- Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull.* 2003;129:946–972.
- Burton LC, Newsom JT, Schulz R, et al. Preventive health behaviors among spousal caregivers. *Prev Med.* 1997;26:162–169.
- Kaiser Family Foundation. *Medigap: Spotlight on Enrollment, Premiums, and Recent Trends*. Retrieved November 5, 2014 from: <http://kaiserfamilyfoundation.files.wordpress.com/2013/04/8412-2.pdf>; April, 2013.
- Hughes ME, Waite LJ, Hawkey LC, et al. A short scale for measuring loneliness in large surveys. *Res Aging.* 2004;26:655–672.
- Kroenke K, Spitzer RL, Williams JBW. The patient health questionnaire-2. Validity of a two-item depression screener. *Med Care.* 2003;41:1284–1292.
- Wallace LS, Rogers ES, Roskos SE, et al. Screening items to identify patients with limited health literacy skills. *J Gen Intern Med.* 2006;21:874–877.
- Charlson ME, Pompei P, Ales KL, et al. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis.* 1987;40:373–383.
- Fairies DEL, Haro JM, Obenchain RL, et al. *Analysis of Observational Healthcare Data Using SAS*. Cary, NC, USA: SAS Institute, Inc.; 2010.
- Seeger JD, Williams PL, Walker AM. An application of propensity score matching using claims data. *Pharmacoepidemiol Drug Saf.* 2005;14:465–476.
- Garand L, Rinaldo DE, Alberth MM, et al. Effects of problem solving therapy on mental health outcomes in family caregivers of persons with a new diagnosis of mild cognitive impairment or early dementia: a randomized controlled trial. *Am J Geriatr Psychiatry.* 2014;22:771–781.
- Hirano A, Suzuki Y, Kuzuya M, et al. Influence of regular exercise on subjective sense of burden and physical symptoms in community-dwelling caregivers of dementia patients: a randomized controlled trial. *Arch Gerontol Geriatr.* 2011;53:e158–e163.
- Loi SM, Dow B, Ames D, et al. Physical activity in caregivers: what are the psychological benefits? *Arch Gerontol Geriatr.* 2014;59:204–210.
- Wakui T, Saito T, Agree EM, et al. Effects of home, outside leisure, social and peer activity on psychological health among Japanese family caregivers. *Aging Ment Health.* 2012;16:500–506.