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## Feature Article

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

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## 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.

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## 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.<sup>1,2</sup> 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.<sup>1,2</sup> The prevalence of caregivers for older adults in the US has been reported to range from about 12% to 19%.<sup>3–5</sup> 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.<sup>6,7</sup> 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.<sup>2,4–8</sup> 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.<sup>1,6,8–10</sup> In contrast, sizable percentages (i.e., estimated at 68%)<sup>2</sup> 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.<sup>3,4,8–13</sup>

Conflicts of interest: None.

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Caregiver research studies have a long history but often focus on subgroups of caregivers associated with selected diseases or conditions.<sup>4,7,9,11–19</sup> 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.<sup>15,20,21</sup> Results are generally self-reported on various surveys or in-person interviews; many with no control groups.<sup>7,9,11–15,17–19</sup> Few randomly selected or representative caregiver studies have been published.<sup>1,3,4,8,22,23</sup> 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%.<sup>6,8,11,12,17,18,22,24</sup> 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.<sup>4,8,12,17,23</sup> Two large meta-analyses concluded slight to no impact on physical health associated with caregiving.<sup>25,26</sup> In addition, reduced rates of mortality have been associated with caregiving.<sup>4</sup> 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)<sup>1,8,24</sup> or those caring for advanced dementia, Alzheimer's disease or other advanced disease conditions.<sup>10,21</sup>

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,<sup>8,18,21</sup> or, in contrast, caregivers handling *more* problem behaviors for their spouses with Alzheimer's disease were significantly *less* likely to be hospitalized.<sup>21</sup> 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.<sup>10,27</sup>

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.<sup>28</sup> While updates of caregiver reports are regularly published,<sup>2,5</sup> 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<sup>®</sup> 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.

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