

**Identifying Families at Risk For Out-of-Pocket Caregiving Costs
Using a U.S. Population-based Sample**

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ABSTRACT. This study focused on out-of-pocket expenditures from informal caregivers providing care to friends or family members. The main objective was to identify families most at risk for out-of-pocket costs associated with caregiving. Cross-sectional data from the “Family Caregiving and Out-of-Pocket Costs 2016”, a national study fielded by the Association of American Retired Persons (AARP), were used. Descriptive analyses and regression modeling were performed, using population weights. We found that caregivers with a child or children in the household had higher odds of out-of-pocket spending than did caregivers with no children in the household (aOR 1.97; 95% CI, 1.42-2.72). A dose-response relationship was present; those with high levels of caregiving burdens were more likely to report out of pocket costs compared to caregivers with a low burden indices (aOR 2.26; 95% CI, 1.66-3.07). These findings highlight the pressing need for further policy and program development targeting informal caregivers, particularly younger caregivers.

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Formal caregiving is not affordable for many individuals, with informal caregivers supplying a substantial portion of all long-term care (Anderson et al., 2013; Freedman & Spillman, 2014; Kemper, Komisar, & Alexih, 2005; Rubin & White-Means, 2009). Limitations of Medicare and the Family and Medical Leave Act also make formal, institutional caregiving more expensive and challenging to acquire long-term. Families must spend down their assets in order to get coverage for caregiving (Rubin & White-Means, 2009). In this environment, informal caregiving is increasing and impacting an ever-broader set of the population. Informal caregivers as defined by the Family Caregiving Alliance are unpaid, part or full-time caregivers for family, friends or neighbors (Family Caregiving Alliance, 2015). Informal caregivers may assist with coordination and provision of services.

Numbers of families with diverse arrangements for informal caregiving are rising. In 2005, it was estimated that approximately 40 million informal caregivers would be in place by 2050 (Family Caregiving Alliance, 2005). However, as of 2015, more than 65 million caregivers are providing informal care to a family member or friend aged 18 or older (Family Caregiving Alliance, 2015; National Alliance for Caregiving & AARP, 2009). In the United States, informal, unpaid caregivers provide most long-term care, with informal caregiving often more intense and lasting for longer periods than does formal caregiving (Navaie-Waliser, Spriggs, & Feldman, 2002; Rubin & White-Means, 2009). As this trend continues, there are increasing concerns with how to provide support, assistance, and policy measures to help these individuals and families without creating an overwhelming burden on the health care system (Rowe, 2012).

This research uses a social support theoretical lens to begin to understand the financial burden of informal caregivers. It also explores the variation in cost burdens across various racial, generational, and other population groups. As formal and institutionalized caregiving becomes more expensive, research exploring financial impacts of informal caregiving is imperative.

Literature and Theory

Social support theory distinguishes among four types of social support: emotional, instrumental, informational, and appraisal (House, Umberson, & Landis, 1988). As informal caregiving increases in the United States, understanding potential challenges in caregiving support is important. The burden of caregiving affects four domains, physical, social, financial, and psychological, and can change over time (Chou, 2000). Several predisposing characteristics that will affect how caregivers will experience burdens. These factors, which include personal demographics, socioeconomic status, health status, social environment, and feelings of obligation or responsibility, will lead caregivers to experience various levels of burden for similar situations (Chou, 2000). Others have indicated that caregiving becomes a primary stressor, which exacerbates the impact of other secondary stressors caregivers experience (Pearlin, Mullan, Semple, & Skaff, 1990). Overall experience of burden is further moderated by coping

mechanisms and social support systems (Chou, 2000). As such, social support theory is a useful lens from which to examine factors impacting the burden of informal caregiving.

While informal caregiving has benefits such as alleviating some of the burden on the health care system, it does not come without costs that include psychological and physical effects, lost wages, pensions, and Social Security benefits (Rowe, 2012). This value has been estimated at \$450 billion (Feinberg, Reinhard, Houser, & Choula, 2011). Additional estimates have valued total costs of informal caregiving at \$3 trillion in lost wages, Social Security benefits, and pensions for people 50+ years caring for their parent(s) (Arno, Viola, & Shi, 2011; Rowe, 2012). These additional estimates suggest that if informal caregiving were replaced with formal care, it would cost approximately \$257 billion in year 2000 dollars, an amount that exceeds the costs associated with home health and nursing home care combined (Arno, 2002). More recent estimates reveal that unpaid caregivers services are valued at approximately \$470 billion annually, providing 37 billion hours of care (AARP, 2017). Therefore, informal caregiving, the related burden, and associated costs are important issues for policymakers, health care providers, and families.

Previous research has demonstrated the burden of informal caregiving, with caregivers reporting higher rates of poor physical and mental health (Anderson et al., 2013; Crouch, Probst, & Bennett, 2017; Trivedi et al., 2013). There may also be generational differences in the burden of informal caregiving, with a generation of individuals “sandwiched” between responsibilities for the care of their children and of their elderly family members (Parker & Patten, 2013; Spillman & Pezzin, 2000). The sandwich generation is argued to be wider than in past decades, is more likely to be middle aged, employed, and married, and to have higher incomes and better health outcomes than other caregivers (Parker & Patten, 2013; Riley & Bowen, 2005; Rubin & White-Means, 2009).

Some groups appear more likely to experience the challenge of caregiving for multiple generations. A 2006 (Pinquart & Sörensen) meta-analysis finds that 69% of informal caregivers in the United States are women. Pew research (Parker & Patten, 2013) finds that over 30% of Hispanic adults report being part of this sandwiched generation, compared to less than 25% of white and black individuals. In 2012, 32.9% of Millennials (aged 18-34), 74.4% of Generation Xers (aged 35-50), 56.1% of Young Baby Boomers (51-70), and 35.6% of Older Baby Boomers (above 70) were included in this group (Wassel & Cutler, 2016). As the proportion of Caucasians 65 years and older in the United States declines, there is a need for additional research on distribution of costs and benefits of informal caregiving across race, ethnicity, and other population groups.

Financially, one third of individuals report they have provided financial support to an aging parent, 65 and older, in the past year and almost 80% report providing most or some help related to handling personal affairs or day-to-day living (Parker & Patten, 2013). Individuals in the “sandwiched” caregiver category reported feeling more responsibility for provision of financial assistance to their parents than to their children (Wassel & Cutler, 2016). Individuals in these roles are more likely to provide regular emotional support to their loved one(s), which

further increases their individual stress burdens, potentially impacting their health and well-being (Parker & Patten, 2013; Rubin & White-Means, 2009).

Approximately 60% of today's workforce can be classified as sandwiched caregivers, compared to between 7% and 40% in the 1990s (Durity, 1991; Parker & Patten, 2013). Starting and continuing in the role of an informal caregiver correlates with reduced work hours and the increased difficulty of regaining full-time employment after caregiving responsibilities end (Ruben & White-Means, 2009; Spiess & Schneider, 2002). Women, caregivers with less education, and first-generation immigrants have been found to face particular challenges with workplace accommodations, culture, and flexibility related to caregiving responsibilities (Lahaie, Earle, & Heymann, 2013). While these findings are connected to labor force issues related to lower wage, hourly, less educated entry level employment, the fact remains that these barriers force employees to make difficult accommodations and, at times, leave the workforce entirely to provide caregiving.

Withdrawal from the labor force has macro- and micro- economic impacts but may also compromise mental and emotional well-being as labor force participation reduces stress and strain of managing multiple caregiving responsibilities (Rubin & White-Means, 2009). Research also documents a greater need for other workplace accommodations, such as unpaid leave, to reduce other economic hardships related to informal caregiving responsibilities (Pavalko & Henderson, 2006). There is also important evidence that caregivers who are able to maintain employment have higher levels of physical, mental, and relationship health (Blau, Ferber, & Winkler, 2006; Campione, 2006).

The financial burden on the caregiver may also be significant. Depending on income, informal caregiving out-of-pocket costs can range from 10-20% or more (Feinberg et al., 2011; Rowe, 2012). Caregivers have also been found to spend less money on themselves or to contribute to savings, investments, and home improvements due to the increased financial costs of caregiving (Arno, Viola, & Shi, 2011; Carers UK, 2007; Evercare, 2007). The most common way of coping with extra out-of-pocket expenses as a result of unpaid caregiving is to eliminate one's social and leisure activities (Duxbury, Higgins, & Schroeder, 2009; Evercare, 2007; Fletcher, Fast, & Eales, 2011; Shooshtari, Duncan, Roger, Fast, & Han, 2017). Very recent analysis in Canada confirms an independent, statistically significant relationship between out-of-pocket spending and care related impacts (Shooshtari et al., 2017). No studies have focused on identifying families most at risk for out-of-pocket caregiving costs using a nationally representative sample in the United States. The purpose of this study was to identify, among caregivers, those families most at risk for out-of-pocket costs associated with caregiving.

Methods

Data

Data for this study came from “Family Caregiving and Out-of-Pocket Costs 2016”, a survey conducted by AARP. Its purpose was to capture the financial strain of caregiving among unpaid, informal caregivers through reporting of costs of assisting care recipients. Diary and survey components were used for calculating annual costs per caregiver for out-of-pocket spending. The GFK’s probability-based online Knowledge Panel was used for conducting this national study in the summer of 2016 (Rainville, Skufca, & Mehegan, 2016). The sample was limited to adults aged 18 or older who participated in a month long diary study and answered yes to the question, “Are you currently provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?” (n=1,864). Unpaid care may include “helping with personal needs or medication management, household chores, or transportation. It might be managing a person’s finances, arranging for outside services, preparing meals or grocery shopping, helping with bathing or dressing, or even visiting regularly to see how they are doing” (Rainville et al., 2016). There was not a length of time mandated for caregivers to care for the recipient in order to be eligible for participation in the study.

Dependent Variables

The principal dependent variable is caregiving cost. This was a calculated sum of out-of-pocket caregiving expenses: medical, household, personal care, education/legal/travel, and personal care/respite services. The burden of costs may differ based on the caregiver’s household income, as well as the number of people in the household. Thus, the cost of care was calculated into two different percentages for each caregiver. The first is those with zero out-of-pocket caregiving expenses and those with non-zero out-of-pocket caregiving expenses. The second is the total out-of-pocket costs as a percentage of total household income, adjusted for household size (annual costs/ (income/household size). These ratios were further divided into categories over all respondents with non-zero out-of-pocket costs. The categories for Annual Costs/ Household Income were less than 8.6% (the 75th percentile for that category) or greater than 8.6%. Annual Costs/(Household Income/Household Size) were less than 20.0% (the 75th percentile for that category) or greater than 20.0%.

Independent Variables

Independent variables included the following socio-demographic characteristics of the caregiver: sex, race, age, education, employment, and income adjusted for household size. Race was grouped into these categories: Non-Hispanic White, Non-Hispanic Black, Hispanic, and Other. Age was categorized into four generations: Millennial (ages 18-34), Generation X (ages 35-50), Baby Boomers (ages 51-70), and Silents (ages 71-90), as there may be generational differences in the burdens of informal caregiving (Strauss & Howe, 1991). Education was categorized into caregivers who had less than a high school degree, a high school degree, some college, or a bachelor’s degree or higher. Employment was defined as whether the caregiver was employed for any number of hours during the last year. Additional independent variables included presence of a dependent child or children in the home (under the age of 18), with a generation of individuals “sandwiched” between responsibilities for the care of their children and

the care of their elderly family members (Spillman & Pezzin, 2000). Residence was categorized into whether or not the caregiver lived in the household with the recipient.

The burden of costs may differ based on the caregiver’s pretax household income, as well as the numbers of people in the household. Thus, total household income adjusted for household size was calculated as income/household size. Income adjusted for household size was categorized into quartiles: annual household income less than or equal to \$11,249.75, annual household income greater than \$11,249.75 but less than or equal to \$22,499.67, annual household income greater than \$22,499.67 but less than or equal to \$39,999.50, and an annual household income greater than \$39,999.50. The income categories reported were not continuous, so there are deviations in the percentages of respondents in each quartile.

Table 1

Construction of the Level of Burden Index

Hours of Care	
0 to 5 hours	1 point
6 to 20 hours	2 points
21 to 30 hours	3 points
Greater than 30	4 points
Types of Care Provided	
0 ADLS, 1 IADL	1 point
0 ADLS, 2 or more IADLS	2 points
1 ADL, 1 or more IADLS	3 points
2 or more ADLS, 1 or more IADLS	4 points
Level of Burden	
Low Burden	2 to 4 points
Medium Burden	5 points
High Burden	6 to 8 points

The level of caregiving burden index, measured with time and physical care, was based on a previous level of burden index developed for AARP and the National Alliance for

Caregiving (NAC) and used in “Caregiving in the U.S. 2015” (AARP, 2015). This index was modified for the variables in this study (Table 1). Points were assigned based on the number of hours providing care (5 or fewer hours=1 point, 6 to 20 hours=2 points, 21 to 30 hours=3 points, more than 30 hours=4 points), as well as the number of activities of daily living (ADLs) and instrumental activities of daily living (IADLS) performed for the recipient. The ADLS and IADLS were combined to create the following variables: 0 ADLs with 1 IADL=1 point, 0 ADLs with 2+ IADLs=2 points, 1 ADL with any number of IADLS=3 points, and 2 or more ADLs with any number of IADLS=4 points.

Activities of daily living included assisting with getting in and out of bed or chairs, getting dressed, getting to and from the toilet, dealing with incontinence or diapers, giving medicines, monitoring blood pressure or blood sugar, feeding him or her, or taking a bath or shower. Instrumental activities of daily living include assisting with grocery shopping, housework or cleaning, transportation, finances, meal preparation, and outside care activities. Five levels of burden were constructed from these points. These levels ranged from 1, with no ADLs and few hours of care, to Level 5, with at least two ADLs and more than forty hours of care per week. Levels of burden were further divided into three categories: low (level 1 and 2; 2 to 4 points), medium (level 3; 5 points), and high burden (level 4 and 5; 6 to 8 points). The categories of low, medium, and high burden were used for this analysis.

Sample

In the total sample of 1,864 caregivers, the majority were female (60.1%), non-Hispanic White (69.4%), had some college or a bachelor’s degree or higher (62.3%), and did not reside in the same household as the caregiving recipient (58.8%; Table 2). The burden of care was low for most of the caregivers (45.2%). Most caregivers (78.2%) had non-zero out-of-pocket expenditures. The generational distribution of caregivers varied, with most caregivers 51 years of age and older (55.5%). Median household income among all caregivers, adjusted for household size, was \$22,499.

Analytic Methods

To calculate frequencies and proportions for each category of variables, standard statistical analysis procedures were used. To account for survey stratification, population weights were used. Bivariate analysis was used to examine differences in groups with expenditures and those without using chi-square tests, $\alpha = 0.05$. Wilcoxon rank-sum tests were used for detecting statistically significant differences in total median and mean expenditures. Logistic regression was performed to examine relationships between independent variables and whether or not caregivers had out-of-pocket cost caregiving expenditures. Analyses were completed using statistical software (SAS, version 9.3; SAS Institute Inc.) Our study was approved by the [name concealed for review] institutional review board.

Table 2

Characteristics of Caregivers, AARP Survey, 2016, by Non-zero and zero out of pocket caregiving costs (N=1,864)

	Total	Non-Zero Expenditures	Zero Expenditures	
		%	%	P-value
Expenditures		78.2	21.8	<.0001
Gender				0.6494
Male	39.9	39.7	40.9	
Female	60.1	60.3	59.1	
Race				0.0530
Non-Hispanic White	69.4	68.4	73.0	
Non-Hispanic Black	8.3	9.1	5.6	
Other	14.9	22.6	21.4	
Generation				0.0587
Millennials (18-34)	19.1	15.0	20.2	
Generation X (35-50)	25.4	24.3	25.8	
Baby Boomers (51-70)	46.4	50.4	45.3	
Silents (71-91)	9.1	10.3	8.7	
Education				0.1718
High School or less	37.7	37.2	39.7	
Some College	33.3	32.8	35.1	
Bachelor's Degree or Higher	29.0	30.1	25.3	
In Household	41.2	40.9	42.2	

Not in Household	58.8	59.1	57.8	
Employed	52.2	53.8	46.4	0.0085
Child/Children in Household	26.7	29.4	16.8	<.0001
Level of Burden				<.0001
Low	45.2	42.5	55.1	
Medium	12.6	13.2	10.6	
High	27.9	30.0	20.3	
Unknown ¹	14.3	14.4	14.1	
Income, adjusted for household size				0.02
Median	\$22,499	\$22,450	\$26,666	
Mean	\$30,651	\$29,929	\$33,245	
Q1	21.6	27.8	24.0	
Q2	26.3	24.0	23.6	
Q3	25.9	25.3	22.1	
Q4	26.2	23.1	30.4	

¹ Included for sample size purposes

Results

In unadjusted analysis, differences in non-zero versus zero expenditures existed among caregivers (78.2% versus 21.8%). Employed caregivers were more likely to have non-zero expenditures than zero expenditures (53.8% versus 46.4%, $p=0.0085$). Caregivers with a child or children in the household were also more likely to have non-zero expenditures than zero expenditures (29.4% versus 16.8%, $p<0.0001$). Caregivers with low levels of burden were less likely to have non-zero expenditures than zero expenditures (42.5% versus 55.1%, $p<0.0001$). Those with medium or high levels of burden were more likely to have non-zero versus zero expenditures (13.2% versus 10.6%, 30.0% versus 20.3%, $p<0.0001$). Median income of caregivers with non-zero expenditures was also lower than the median income of caregivers with zero expenditures (\$22,450 versus \$26,666, $p=0.02$).

In analyses adjusting for generation, gender, race, education, residence, and income, caregivers who were employed more likely to report out-of-pocket caregiving costs than their non-employed counterparts were (aOR 1.42; 95% CI, 1.10-1.82; Table 3). Caregivers with a child or children in the household had higher odds of out-of-pocket spending than did caregivers with no children in the household (aOR 1.96; 95% CI, 1.42-2.70). Caregivers with medium levels of burden were more likely to report out-of-pocket costs than their counterparts with low levels of burden (aOR 1.67; 95% CI, 1.15-2.43). A dose-response relationship was present, with those with high levels of burden more likely to report out-of-pocket costs compared to caregivers with low burden indices (aOR 2.33; 95% CI, 1.72-3.16). Finally, caregivers with income in the third quartile were significantly more likely to report out-of-pocket caregiving costs than were caregivers in the fourth income quartile (aOR 1.55; 95% CI 1.12-2.16).

Table 3

Factors Associated with Out-of-Pocket Caregiving Costs, AARP Survey, 2016

	Adjusted Odds Ratio (95% CI)
	Non-zero Out-of-Pocket Caregiving Costs, total
Caregiver Characteristic	
Generation	
Millennials (18-34)	Referent
Generation X (35-50)	0.74 (0.51-1.07)
Baby Boomers (51-70)	0.88 (0.61-1.27)
Silents (71-91)	0.98 (0.59-1.62)
Gender	
Male	Referent
Female	1.04 (0.82-1.31)
Race	
Non-Hispanic White	Referent
Non-Hispanic Black	1.57 (0.97-2.55)

Other	1.01 (0.75-1.35)
Education	
High School or Less	Referent
Some College	0.98 (0.74-1.30)
Bachelor's Degree or Higher	1.45 (1.05-2.01)
Residence	
In Household	0.77 (0.60-1.00)
Not in Household	Referent
Employed	1.42 (1.10-1.82)
Child/Children in Household	1.96 (1.42-2.70)
Level of Burden	
Low	Referent
Medium	1.67 (1.15-2.43)
High	2.33 (1.72-3.16)
Income quartiles	
Q1	1.44 (0.96-2.17)
Q2	1.39 (0.97-1.98)
Q3	1.55 (1.12-2.16)
Q4	Referent

Among caregivers with non-zero expenditures, there were generation differences for those spending greater than 8.6% of their household income on out-of-pocket caregiving costs, and for those spending greater than 20.0% of their household income on out-of-pocket caregiving costs, adjusted for household size (Table 4). Baby boomers and seniors were less likely to spend greater than 8.6% of their annual household income on out-of-pocket caregiving costs (aOR 0.55; 95% CI, 0.30-0.98; aOR 0.46; 95% CI, 0.25-0.86). Non-Hispanic Black caregivers had higher odds of spending greater than 8.6% of their annual household income on

out-of-pocket caregiving costs (aOR 2.49; 95% CI, 1.39-4.48). Co-residential caregiving relationships were significantly more likely to have spending greater than 8.6% of their annual household income on out-of-pocket caregiving costs (aOR 1.81; 95% CI, 1.23-2.67). Caregivers with high levels of burden were more likely to report larger percentages of out-of-pocket costs, compared to caregivers with low burden indices (aOR 1.81; 95% CI, 1.10-3.00). Finally, odds of spending greater than 8.6% of their annual household income on out-of-pocket caregiving costs declined with education levels. These same trends held true for spending greater than 20.0% of household income, adjusted for household size.

Table 4

Factors Associated with High Out-of-Pocket Costs, AARP Survey, 2016, Out of pocket caregiving costs as a ratio of Household Income and as a ratio of Household Income/Household Size

	Adjusted Odds Ratio (95% CI)	
	Greater than 8.6% (Costs/Household Income) ^a	Greater than 20% (Costs/(Household Income/Household Size) ^b
Caregiver Characteristic		
Generation		
Millenials	Referent	Referent
Generation X	0.76 (0.40-1.44)	0.56 (0.30-1.04)
Baby Boomers	0.55 (0.30-0.98)	0.35 (0.19-0.62)
Senior	0.46 (0.25-0.86)	0.28 (0.15-0.52)
Gender		
Male	Referent	Referent
Female	1.11 (0.78-1.58)	1.12 (0.79-1.60)
Race		
Non-Hispanic White	Referent	Referent
Non-Hispanic Black	2.49 (1.39-4.48)	2.17 (1.20-3.94)

Hispanic	1.03 (0.63-1.69)	1.18 (0.73-1.92)
Other	1.32 (0.64-2.75)	0.99 (0.46-2.15)
Education		
Less than High School	Referent	Referent
High School	0.19 (0.09-0.41)	0.34 (0.16-0.72)
Some College	0.18 (0.08-0.42)	0.32 (0.15-0.68)
Bachelor's Degree or Higher	0.17 (0.08-0.36)	0.29 (0.14-0.62)
Residence		
In Household	1.81 (1.23-2.67)	1.76 (1.19-2.60)
Not in Household	Referent	Referent
Employed	0.79 (0.54-1.15)	0.71 (0.49-1.03)
Child/Children in Household	1.14 (0.74-1.77)	2.04 (1.34-3.12)
Level of Burden		
Low	Referent	Referent
Medium	1.81 (1.10-3.00)	2.89 (1.77-4.73)
High	2.97 (1.99-4.43)	3.19 (2.12-4.80)

^a Relative to caregivers who spent less than 8.6% of their income on out of pocket costs related to caregiving, adjusted for household income

^b Relative to caregivers who spent less than 20.0% of their income on out of pocket costs related to caregiving, adjusted for household income and household size

Discussion

This paper is the first to identify, among caregivers, families most at risk for out-of-pocket costs associated with caregiving in a nationally representative sample of caregivers in the United States. Previous research focused on a subset of caregivers or were based in countries with single-payer health insurance (Feinberg et al., 2011; Rowe, 2012; Shooshtari et al., 2017). We found a dose-response relationship between levels of burden and non-zero out-of-pocket caregiving costs, with higher levels of burden increasing the odds of non-zero out-of-pocket

caregiving costs. This relationship between caregiving burdens and financial obligations is not a given and thus is an important finding for policymakers and families.

An important finding in this research is the significance of a child or children in the household and non-zero out-of-pocket caregiving costs. This is critical to understanding potential generational differences among informal caregivers. Younger caregivers may be sandwiched between their caregiving roles and other responsibilities (such as raising children) that contribute to costs and emotional burdens of caregiving (Fruhauf, Jarrott, & Allen, 2006). Therefore, demographic shifts in the country, such as aging of baby boomers, have potential to impose substantial costs on individuals, families, and health systems.

As demand for caregiving increases, the nature of caregiving responsibility and costs may fall disproportionately on some groups in comparison to others. For example, Millennials are more likely to have children at home, to hold substantial debt as a group, and partly because of this may delay major life purchases like cars and homes, and major life decisions like getting married, among others (DeVaney, 2015). If, at the same time, more Millennial adults are becoming caregivers and realizing financial burdens from this, this may result in more financial strain on this group and may further impact the broader economy. Similarly, uneven workplace impacts for women, entry level employees, and immigrants underscore additional stressors and potential financial burdens that may fall disproportionately on these groups (Lahaie et al., 2013).

Among caregivers with non-zero expenditures, we found that co-residing households were more likely to have higher cost burdens than do those not co-residing. This indicates a need for targeted services and support for families that co-reside with caregiving recipients. Our findings also reveal that Non-Hispanic Black families have higher financial burdens in comparison to other groups. This may be shared disproportionately across non-Hispanic Black generations, further exacerbating ongoing educational, wealth, and other socioeconomic disparities.

Racial and ethnic groups may manage caregiving responsibilities differently based on social, cultural, or other influences, thus experiencing different burdens (Skarupski, McCann, Bienias, & Evans, 2009). Pinqart and Sörensen (2005) find that minority groups in general provide more care than do their non-minority peers; others find that African Americans report less burden and more caregiving satisfaction than do White caregivers (Haley, Wadley, West, & Vetzal, 1994; Lawton, Rajagopal, Brody, & Kleban, 1992; Pinqart & Sörensen, 2005). African Americans have also been found to have lower rates of depression than do White and Hispanic caregivers of dementia patients (Covinsky et al., 2003). A 2002 study (Dilworth-Anderson, Williams, & Gibson) finds that these differences may be driven by the density and depth of informal social networks. This is important because there is increasing evidence of the importance of informal social networks to the health and well being of elderly patients and their caregivers (Bishop, Martin, & Poon, 2006; Levitt, Antonucci, Clark, Rotton, & Finley, 1985; Litwin & Shiovitz-Ezra, 2006; Pinqart & Sörensen, 2000; Yang, 2006).

These results point to the need for targeting programs to specific communities and populations. For example, changing demographic patterns may amplify informal caregiving

trends in different ethnic, racial, or population groups, such as sandwiched caregivers. Policy considerations such as tax credits, formalized leave policies, and even specific “payment” opportunities for informal caregivers could be considered (Arno, Levine, & Memmott, 1999; Lai, 2012). Considering state and federal level policies around balancing employment responsibilities for caregivers and economic incentives for caregiving choices are imperative in supporting families in their informal caregiving responsibilities. Changes to Medicare in the late 1990s reduced Medicare home health coverage and the Family and Medical Leave Act does not cover long term care, creating a stronger need for many families to provide informal caregiving (Rubin & White-Means, 2009). Traditional approaches like community healthcare networks and other community programming efforts (e.g. respite care, support networks) are also important to ensuring that cultural and individual choices of different populations are met.

Several recent federal policy measures promoting in-home family care have passed or been proposed. Federal caregiving initiatives such as the Older Americans Act, the National Family Caregiver Support Program, and the Lifespan Respite Program are important sources of support for unpaid caregivers (Monahan, 2013). The 2006 Lifespan Respite Care Act authorized \$300 million over five years to flow through the states to families hiring temporary in-home care assistance (Lovley, 2006). The Community Living Assistance Services and Supports (CLASS) Act, which would have been a federal long-term care insurance program, was created as a cash benefit to hire family caregivers in 2010. This program was repealed in 2013 as it was part of the Patient Protection and Affordable Care Act (Miller, 2011).

For caregivers residing in rural communities, consumer-directed models such as the CLASS act would have provided unique types of support they may need more than their urban counterparts (Chadiha, Feld, & Rafferty, 2011). The AARP Public Policy Institute has numerous recommendations to meet the needs of informal caregivers, such as expanding the Family and Medical Leave Act, providing pay to caregivers through Medicaid and Medicare, and barring discrimination workers who also act as caregivers may face (Feinberg, 2013). Other policy ideas include federal and/or state tax deductions for informal caregiving, direct subsidies or tax deductions for in-home caregiving options, subsidies for respite care, and family caregiver compensation through wages or cash grants (Rubin & White-Means, 2009).

Social support theory underscores the importance of elements of instrumental, financial, informational, and emotional support. Research documents that the nature of caregiving burden is impacted by many things including differences in education, age, and gender. Previous research on informal caregiving has documented the outsized roles of women in informal caregiving roles and the need for service providers to target programs towards specific needs of caregivers (Calasanti & King, 2007; Gregory, Peters, & Cameron, 1990; Lai, 2012; Litz, Zeiss, & Davis, 1990; Wong, 2005). Research has further documented the importance of education and age to whether caregivers may find themselves burdened by their caregiving roles (Himes, Jordan, & Farkas, 1996; Stolley, Reed, & Buckwalter, 2002). These studies highlight the need for creative policies and programs that support caregivers with (a) instrumental support, such as respite care, grocery shopping, and doctors’ appointments; (b) opportunities for financial relief and assistance; (c) informational services related to caregiving resources; and (d) emotional support with community groups, respite care, counseling support and others. Our research

reveals that the financial component of informal caregiving must be considered if we are going to improve outcomes for informal caregivers and those for whom they care.

This paper underscores the importance and diversity of informal caregiving choices and situations. When evaluating policy choices it is important to recognize this diversity and target policy accordingly. This research contributes to the literature in several key ways. It confirms that out-of-pocket spending for informal caregiving varies across groups and can be a major economic barrier for individuals taking on these responsibilities. It adds to the limited research stream on variation of informal caregiving burdens among generational groups. In this vein, it highlights the need for additional research on the impacts on Millennial and Generation X caregivers and the potential economic impacts of these choices on individuals and families. Finally, this analysis stresses the need for new policy measures that potentially provide targeted support to informal caregiving groups like sandwiched caregivers and some racial and ethnic groups.

Our study has several limitations. First, diary reporting of spending is a limitation due to concerns of reliability, accuracy, and potential bias. Future research should consider other sources of cost and/or lost income data. Data limitations include information on lost wages as well as the opportunity cost of lost wages for caregivers who have reduced work hours or who choose to work part time. Despite these limitations, our findings demonstrate the need for future research on generational impacts of informal care burdens, with a focus on a wider range of costs burdens. Research addressing challenges and potential sacrifices specific to generational groups through quantitative and/or qualitative means would also be valuable.

Informal caregiving imposes emotional, physical, and financial costs on individuals, families, and society. With informal caregiving projected to absorb a larger share of overall caregiving responsibilities, developing formal policy and programs in support of these choices is imperative. In September 2017, Congress proposed the RAISE Family Caregivers Act. This Act would bring public and private stakeholders together to develop targeted strategies and actions for communities, government, and healthcare providers to support and coordinate family care of loved ones (AARP, 2017). This type of multi-faceted, multi-stakeholder effort would be an opportunity to better understand distribution of costs, benefits and burdens across society.

These findings highlight the importance of informal caregiving for meeting the needs of increasing numbers of Americans. While these situations vary, informal caregiving can be considered an important complement to formal caregiving and one that has potential to reduce demands for formal caregiving services. As such, programs and policies should be considered across communities and organizations to help families manage financial burdens of informal caregiving. As this research has shown, the out of pocket financial burden varies across generational groups. Understanding methods to help minimize this burden could keep millions of Americans in their homes and reduce healthcare costs and burdens of formal caregiving.

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