WHICH LTSS FINANCIAL SUPPORT POLICIES ARE PREFERRED AMONG CAREGIVERS AND CAN THEY REDUCE RACIAL/ETHNIC DISPARITIES IN RETIREMENT SECURITY?

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Abstract

While family caregivers are the backbone of the long-term services and supports (LTSS) system of care, caregiving is challenging and often comes at a financial cost for caregivers, from both the direct costs incurred in providing care and the reduced labor market earnings in order to provide caregiving. As a result, many caregivers could end up jeopardizing their own retirement security. While the need for better supports is clear, what is less understood is which policies would be most beneficial in alleviating financial burdens associated with caregiving and whether different policies are more effective for or favored by different racial/ethnic groups. Existing policies to alleviate direct out-of-pocket costs or labor market costs for family caregivers are often limited and piecemeal, and vary dramatically by state. This project uses a mixed methods approach to understand which policy proposals would be most beneficial for different groups of caregivers.

The paper found that:

- Focus group participants across all socioeconomic and demographic groups preferred direct monetary compensation for caregiving or reimbursements for out-of-pocket costs.
- Participants' least favored policy was paid family leave.
- Responses align with the quantitative analysis, showing that caregivers would receive the most financial benefit from being paid directly.

The policy implications are:

- Caregivers, particularly caregivers from diverse backgrounds face large financial costs for caregiving and prefer policies that alleviate those costs.
- Much of the policy discussion has focused on forms of paid leave, which is one of the least popular polices among caregivers.

Introduction

Family caregiving serves as the cornerstone of long-term services and supports (LTSS) care for older adults, especially within underserved communities, yet it poses significant challenges and often requires financial sacrifices from caregivers. Researchers, practitioners, and policymakers alike have proposed various options to alleviate this financial strain, but it remains uncertain which options would help caregivers the most. Importantly, caregivers' preferences for policy alternatives may vary by socioeconomic and demographic characteristics (e.g., working versus non-working, high- versus low-income, and racial/ethnic group).

This project uses a mixed methods approach to understand which policy proposals would be most beneficial or favored for different groups of caregivers. The qualitative portion of the analysis is based on focus group interviews with a diverse contingent of LTSS family caregivers to understand which policies they believe would improve their retirement security the most. The focus group discussions are supplemented with analysis of data from the *National Health and Aging Trends Study* (NHATs), linked with the *National Study of Caregiving* (NSOC), to examine which types of caregivers could benefit more from certain policies and how they align with the qualitative responses. The results provide researchers and policymakers with a better understanding of how caregivers view different support policies and whether preferences vary by racial/ethnic and other characteristics.

The discussion proceeds as follows. The first section explores the various policies that may alleviate the financial burden on family caregivers. The second section discusses our focus group design as well as the data and methodology for our complementary quantitative analysis. The third section presents the results and shows that focus group participants across all groups prefer direct payments for family caregiving or reimbursement for caregiving-related expenses over tax credits, Social Security credits, or family leave provisions. The quantitative analysis helps explain why direct payments are viewed so favorably among caregivers. The final section concludes that while much of the policy discussion has focused on paid leave, this option is among the least preferred policies.

Literature Review

In 2021, about 38 million family caregivers in the United States provided an estimated 36 billion hours of care to an adult with limitations in daily activities, representing the vast majority of care provided to older adults (Reinhard et. al, 2023). While family caregiving is the backbone of LTSS care, particularly for underserved communities, it is challenging and often comes at a financial cost for caregivers, from both the direct costs incurred in providing care and the reduced labor market earnings in order to provide caregiving. As a result, many caregivers could end up jeopardizing their own retirement security.[1]

Currently, more than one-third of LTSS care is paid for out-of-pocket (Johnson and Dey 2023). If care recipients do not have enough income or assets to cover care needs, much of the financial burden falls on the caregiver. The costs associated with caregiving can include paying caregivers directly or incurring direct expenses such as making home modifications or additions, or acquiring more accessible transportation options. A recent AARP survey found that 78 percent of caregivers have out-of-pocket costs for providing care. On average, these costs represent 26 percent of caregiver income (Skufca and Rainville 2021**)**.

The larger financial cost for caregivers is the labor market cost. Prior research has found that family caregivers are more likely to reduce the number of hours worked, switch to jobs that are less demanding with lower pay, stop working altogether, or retire early due to caregiving responsibilities (Ettner 1996; Skira 2015; Van Houten, Coe, and Skira 2013; Fahle and McGarry 2017; and Truskinovsky and Maestas 2017). Not surprisingly, caregivers who provide more care face a larger negative impact on their work and earnings. Caregivers who provided more than 20 hours of care a week were twice as likely to miss work (Wolff et al. 2016) and much more likely to cut back hours or pay or retire early (Feinberg 2019 and Jacobs et al. 2017) than caregivers who provided fewer than 20 hours a week. Even short-term caregiving, however, can have labor market consequences, such as needing to take leave or the lack of flexibility.

Policymakers have proposed ways to ease the financial burden on family caregivers. While the need for better support is clear, what is less understood is which policies would be most beneficial and whether different policies are more effective for different racial/ethnic

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[1] For an extensive review of the literature, see Lai (2012); Wilcox and Sahni (2022); and Maestas, Messel, and Truskinovsky (2023)**.** For more on the costs that caregivers incur for providing care, see White-Means and Rubin (2004). Estes et al. (2013) explore how financial costs can cause caregivers financial hardship.

groups. Existing policies to alleviate direct out-of-pocket costs or labor market costs for family caregivers are often limited and piecemeal, and vary dramatically by state. As a result, take-up for many of these policies is limited.

Family caregivers could claim the Child and Dependent Care Tax Credit (CDCTC) to cover some of the out-of-pocket costs of caregiving (Faverault and Spillman 2018). The maximum amount of the credit is $3,000 if you have one dependent and $6,000 if you have two or more. However, the credit is non-refundable, and the caregiver must itemize their deductions. The credit also only applies to costs incurred so the caregiver can work or look for work and does not cover other costs such as home modifications or additions. And, importantly, since the credit only covers costs to help the caregiver remain working, caregivers who are retired do not qualify. As a result, few caregivers of older adults claim the credit (Crandall-Hollick and Boyle 2021). Caregivers who do not qualify for the CDCTC can apply for the Credit for Other Dependents, but the maximum amount is only $500 per year.

Policies to help reduce the labor market costs of caregiving are also limited. Some employers may offer limited paid leave or generous vacation or sick time that can be used for caregiving responsibilities. But typically, workers with access to these benefits are higher earners who work for large employers. Workers without generous employer-sponsored paid leave or vacation/sick time may be eligible for the federal Family and Medical Leave Act (FMLA), which provides up to 12 work weeks of unpaid job-protected leave during any 12-month period for qualifying medical and family reasons (U.S. Department of Labor 2023). While the FMLA offers valuable job protection, many low- and moderate-income workers would face substantial financial hardship from 12 weeks of unpaid leave.

As a result, 14 states have stepped in to provide limited periods of paid family leave (PFL). The number of weeks and amount of income replaced vary across states (Quinby and Silciano 2021; and Coile, Rossin-Slater, and Su 2022). For example, Massachusetts, where the focus groups were conducted, allows for a maximum of 25 weeks of paid leave, of which 12 weeks can be used for family caregiving. Neighboring Rhode Island, however, allows for a maximum of 30 weeks of paid leave a year but only allocates up to 6 weeks for family caregiving (Bipartisan Policy Center 2024). Researchers have found that PFL has helped the wives of care recipients remain working, although has had only a limited impact on husbands (Coile, Rossin-Slater, and Su 2022). The value is larger for workers with a high school degree or less, suggesting that states with PFL could close the differential costs of caregiving. A limitation to many of the studies examining PFL, however, is that PFL is not restricted to workers who provide care to older adults. PFL may be better suited for other forms of caregiving that are expected and of limited duration; caregiving for older adults is often unexpected and the duration undetermined.

In short, employer-based leave policies, federal FMLA, and state PFL are certainly beneficial for short periods of caregiving but provide limited support for primary caregivers who provide care for longer periods. Additionally, many workers do not have access to these programs. Less than 60 percent have access to FMLA (Rossin-Slater and Stearns 2020), and 36 states do not have state-level PFL. Even when workers do have access to the program, take-up is low. For instance, in 2022 only 49,231 caring claims were filed with the California PFL program, representing about one percent of all informal caregivers in the state (California Employment Development Department 2023; Bana, Bedard, and Rossin-Slater 2020; Reinhard et al. 2023; and Hartmann and Hayes 2021).

What Policies and Supports Would Caregivers Prefer?

Recently, some new research has tried to examine what caregivers actually need or want. Qualitative analysis revealed that family caregivers have diverse needs and recommendations, ranging from caregiver pay to improved access to respite care to medical training (Nadash, Tell, and Jansen 2023 and Nadash et al. 2021). Similarly, a recent AARP survey found that caregivers would find many policies – including income tax credits, caregiver pay, and partial paid leave – helpful.

What is less clear is why take-up of existing programs is so low, which policies would be most beneficial, and whether different policies are more effective for different racial/ethnic groups. Policy preferences may differ because the effectiveness of existing policies and caregiver responsibilities vary by race/ethnicity and income. Janevic and Connell (2001) found that the relationship between caregivers and care recipients, which themselves vary by racial/ethnic group, can impact the effectiveness of different policies. For example, White caregivers are more often spouses, while children and extended family caregivers are more often from other racial/ethnic groups. So, the current CDCTC will be less beneficial to retired spousal caregivers. Minority racial/ethnic groups are more likely to provide intensive care and care for family members with dementia (Friedman et al. 2015). Existing leave policies will have limited benefits for long-duration, high-intensity caregivers.

This study conducts four focus groups to examine if policy preferences vary by income level, employment status, race/ethnicity, and whether the caregiver is the primary caregiver. It then uses quantitative analysis to see whether the ranking by focus group participants is consistent with the possible payoff to the policies.

Data and Methodology

This section first discusses data and methodology for the focus group analysis and then describes the approach taken for the quantitative analysis.

Focus Groups

The focus-group interviews involved a diverse array of LTSS family caregivers of older adults. It used a discussion guide, informed by the project objectives and literature review, to elicit views on concrete caregiver support policies. The focus was on understanding how the participants' lived experiences shape their perspectives and on identifying which policies they perceive as most conducive to enhancing their retirement security.

Recruitment of focus group participants was facilitated by SAGO, a firm specializing in engaging individuals from underserved communities for focus groups. Leveraging SAGO's expertise, participants were strategically selected to encompass diverse perspectives reflective of the caregiver population. A stipend of $135 was offered to all participants to enhance their engagement and mitigate potential barriers. The focus groups were conducted virtually to maximize accessibility. To ensure representation of underserved communities, an oversampling strategy was implemented for Blacks, individuals earning lower incomes, and men. A total of 25 caregivers participated, distributed across the four focus groups, with each group comprising 6-8 participants. The segmentation of participants was based on income. Two groups were comprised of higher-income individuals (>$75,000) and two were lower-income (<$75,000). Each of the focus group discussions was recorded and transcribed. The results were analyzed using the qualitative data analysis software package NVivo. While results from focus groups cannot be generalized to a broader population, they provide insights from individuals from disadvantaged communities who are often not heard and provide a context for the quantitative results.

Quantitative Analysis

The quantitative portion supplements the interviews by estimating the extent to which racial/ethnic groups could benefit from the various support policies and by how much. The analysis uses the *NHATS*, linked with the *NSOC*, to first calculate the probability that caregivers from different racial/ethnic groups face various financial challenges due to caregiving. To understand who might benefit involves estimating four regressions:

$$Pr(caregiver\ challenge_i) = \beta_0 + z_i'\beta_1 + \varepsilon_i$$

where the dependent variable is whether the caregiver has experienced financial challenges such as: 1) faced out-of-pocket costs for caregiving; 2) worked part-time; 3) was not in the labor force (and not retired); or 4) lacked flexible hours. A vector of controls, z_i, include race/ethnicity, level of caregiving, and other sociodemographic variables.

The next step is to conduct back-of-the-envelope estimates of how specific policies might improve caregivers' financial security**.** For example, the analysis estimates how providing everyone with 12 weeks of paid leave or paying caregivers $15/ hour for those who provide more than 60 hours of care a month would improve caregivers' finances. The goal is to determine how different policies might help caregivers from different racial/ethnic groups. The results are then compared to the focus group responses.

Results

Focus Group Discussion of Caregiver Support Policies

The following policies were explored with caregivers to assess their perceived helpfulness (that is, value) and to elicit views on each policy. The policies included: 1) paid family and medical leave or expanded paid sick leave; 2) direct payment from the government for providing family care; 3) tax credits for providing care; 4) caregiver credits toward Social Security benefits, such as the Social Security Caregiver Act; 5) paid respite care; and 6) reimbursements for caregiver out-of-pocket expenditures. See Table 1 for a detailed description of the policies discussed.

Table 2 presents the characteristics of the participants from all four focus groups. The final sample included 25 individuals. Respondents were, on average, 50.3 years old (*SD* = 9.9, range 26-67). Overall, the sample was 80 percent female (*n* = 20) and 20 percent male (*n* = 5). A majority of the sample was comprised of individuals drawn from underserved communities including African American (40 percent), Hispanic or Latinx (8 percent), Pacific Islander or Native Hawaiian (4 percent), and Asian (4 percent). Only 44 percent of the sample was White. On average, 60 percent of the sample was employed full-time or part-time (including self-employment). Twenty percent of the sample were retired or partially retired, and 20 percent were full-time homemakers or not employed outside the home. Approximately 52 percent of the sample made less than $75,000 annually, while 48 percent reported making $75,000 or above. Most respondents identified as the primary caregiver for the person they cared for (64 percent), while 36 percent reported sharing caregiving duties with others.

Presented below are participants' reactions to each of the six options.

(1) Paid Family Leave (PFL). While the FMLA is a federal program that protects workers' jobs if they take short leaves to provide care for family members, it is unpaid. Some states have established paid leave programs that replace a portion of workers' wages for a short period of time.[2] Many respondents were aware of and noted the program's positive aspects but many also acknowledged that such a program would not help them in their current circumstances, primarily because they were no longer working. One respondent shared a positive experience, mentioning how the program allowed them to care for a family member while maintaining their job and receiving payment. Another respondent acknowledged the potential benefits but had not used the program because of the availability of greater remote work during the COVID-19 pandemic. A third respondent recognized the potential assistance the program could offer, particularly for those employed outside the home.

Concerns included the program's limitations, such as benefit caps, the limited time that benefits are available, and relevance to certain employment types. Self-employed individuals questioned its relevance, and working caregivers were more likely to highlight the need for job protection. Table 3 highlights some of the participant reactions to PFL or expanded leave as it pertains to caregiving.

(2) Direct Payment for Family Caregiving Services. Most participants showed great interest in being paid directly by the government for their caregiving time. They emphasized the immediate relief such payments could provide, especially in urgent situations, and how it could ease balancing work and caregiving. Concerns about this type of program included anticipated delays in receiving payments, the temporary nature of support, and accessibility issues like

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[2] Bipartisan Policy Center (2024).

eligibility criteria and lengthy approval processes. Disparities in regional availability were also noted as a limitation. Respondents suggested streamlining approval processes and expanding coverage to ensure equitable access to support services. Table 4 highlights some participant reactions to direct payments for family caregiving.

(3) Tax Credit for Caregiving Services. An income tax credit for caregiving for an older adult interested fewer respondents, but some still found it relevant. Participants noted it might not benefit them if they do not pay taxes or prefer immediate assistance. Some found direct government payments far more helpful than a tax credit. Concerns about a tax credit approach included having to wait until tax season to receive the credit. While a tax credit received less enthusiasm than other proposals, it remains a consideration for a subset of caregivers who could benefit from financial relief through reduced income taxes. Table 5 highlights some of the reactions to tax credits for family caregiving.

(4) Social Security Caregiver Credit Act. This policy involves counting caregiving time out of the labor force as "employment" for the purposes of accruing Social Security benefits.[3] Few participants showed interest in this policy in large part due to its focus on future, rather than immediate, financial needs. The fact that such a program could augment Social Security for caregivers unable to work outside the home was viewed positively. Interestingly, higher-income caregivers found this policy more helpful than lower-income earners. Again, some preferred immediate financial support over uncertain future benefits. Suggestions for strengthening such an approach included combining immediate support with long-term benefits to better address caregivers' financial needs. Table 6 highlights some reactions to a Social Security caregiver credit.

(5) Paid Respite Care. Paid respite care involves payments to a provider to give caregivers a short-term break, either through home care services or short-term residential care for the recipient.[4] A modest number of respondents showed interest, seeing potential benefits in reducing caregiver burden and allowing for temporary breaks. The benefits highlighted included

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[3] There are several proposals that aim to help workers who have to drop out the labor force temporarily. Many are focused on caregivers for children but the Social Security Credit Act, which has been introduced in several recent legislative sessions, would apply to those who provide care for children or adults.

[4] The settings in which respite care is provided can vary by state. For example, Massachusetts has a grant that allows home-and-community-based services, such as certified home health agencies and day programs to provide respite care for caregivers. For more information, see: https://www.mass.gov/info-details/respite-innovations-grant . Several states also provide adult day care services, which although not specifically respite care, can help caregivers get a break.

improved time management and opportunities for self-care. Concerns focused on respite care quality, availability, and safety, and care recipient compliance. Overall, respondents found respite care helpful but emphasized the need for adequate payment to ensure high-quality providers. Table 7 highlights some reactions to paid respite care.

(6) Reimbursement for Caregiving-Related Costs. This policy involves covering caregiver spending on items such as home modifications and assistive devices, including adding ramps, building accessible bedrooms, or modifying cars for wheelchairs. Respondents saw significant benefits to such a policy, noting how these reimbursements could improve caregiving duties and quality of life. This policy was viewed as promising since such expenses are often not covered by insurance. While some did not see immediate benefits for themselves, they recognized its potential for others. Concerns included the reimbursement process and the speed of receiving funds. Table 8 highlights some reactions to such a reimbursement policy.

Policy Priorities and Differences by Socio-Demographic Characteristics

Of the six policies described, being paid directly by the government for family caregiving was the most popular, followed by reimbursing caregiving costs (see Figure 1). Specifically, 11 focus-group participants (44 percent) selected direct payments for family caregiving services as the most helpful policy to alleviate financial burdens. This policy option was followed by reimbursing certain caregiving-related costs, which was selected by 6 focus group respondents (24 percent). Having paid respite care and receiving caregiver credit for Social Security benefits were each favored by only 2 participants (8 percent). None of the participants identified paid FMLA or expanded paid sick leave as the most important policy. Not surprisingly, the policies that respondents found least important were almost a mirror image of the ones they found most important (see Figure 2).[5]

While the most important and least important policies were highly consistent across sociodemographic groups, there were some variations. Higher-income caregivers clearly preferred direct payments for caregiving (28 percent), while lower-income caregivers were split

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[5] None of the respondents selected direct government payment or reimbursement for caregiving costs as the “least important” policy. On the other hand, most respondents chose having paid family and medical leave or expanded paid sick leave as the least important (36 percent), followed by receiving a tax credit on income taxes (28 percent) and receiving credit toward Social Security (24 percent).

between reimbursements for caregiving costs (20 percent) and direct payments (16 percent).[6] Higher-income caregivers were more likely to prefer credit for Social Security or paid respite care over reimbursements for caregiving costs (see Figure 3).

Both non-White and White caregivers ranked direct payments highly, but non-White caregivers were more likely to favor direct payments (32 percent vs 12 percent). White participants were also just as likely to rank credit towards Social Security as their preferred policy as direct payments. The second most preferred policy among non-White participants, however, was having costs related to caregiving costs reimbursed (16 percent). Figure 4 summarizes the responses by race. Being paid directly for family caregiving also ranked highly across all employment groups. However, the responses were more scattered across the various policies (see Figure 5).

Not surprisingly, primary caregivers preferred direct payments (32 percent) or reimbursements (16 percent). Non-primary caregivers also liked reimbursements (8 percent) but showed some interest in respite care as well (8 percent). Figure 5 summarizes the responses by caregiver status. See Box (on the next page) for additional themes and considerations for improvement in caregiver support services.

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[6] As previously mentioned, a threshold of $75,000 was used for segmentation of income, with two groups composed of higher-income earners and two comprising lower-income earners. For the purposes of this paper, income was measured by previous year's earnings, and did not consider net worth or additional resources.

Box. Additional Themes and Considerations for Improvement in Caregiver Support Services

Most of the focus group discussions were about how various policies may help the participants with the financial burden of providing care. Participants also provided insight into other improvements that may alleviate some of the caregiving burdens. The following section highlights additional considerations and key areas for improvement in caregiver support services.

Improved Communication: Participants emphasized the need for better communication channels to inform families about available services for caregivers and disabled individuals. Many expressed feeling lost and unaware of support options until guided by others. They suggested the importance of making information more accessible and widely available to aid caregivers in navigating resources effectively.

> *"There needs to be a better means of communicating with families when you have a disabled person as to what services are available. You're lost. Unless someone can guide you and tell you what is available, there's no way to know. That's my biggest challenge. If it weren't for the senior center and volunteers there who helped guide me through different programs, I wouldn't know about them, and there's a lot of people that don't have that ability to get that information."*

Enhanced Services for Older and Disabled Individuals: Participants called for prioritizing services for older and disabled individuals, acknowledging their challenges and the need for tailored support. They emphasized the difficulty of balancing caregiving responsibilities with personal obligations and stressed the importance of additional support to alleviate caregiver burden.

> *"I would say more services for people who are, in my case, older. I know you don't have to be older to be disabled, but something that prioritizes these people more who are elderly or disabled. It's so difficult and with a family member, it's even more difficult because it's your obligation. It's hard to keep a balance between being a caregiver and a daughter. More support is needed. Sometimes, I feel like nobody understands what it's like."*

Quantifying Challenges for Caregivers

One reason that policy preferences vary across sociodemographic groups may be because the characteristics of caregivers and the level of care they provide differ. Data from NHATS/NSOC show that Black and Hispanic caregivers are younger and much more likely to be the children or grandchildren rather than spouses of care recipients compared to their White counterparts (see Figure 7). As a result, 34 percent of Black and 41 percent of Hispanic caregivers are under age 50 relative to 22 percent of White caregivers (see Figure 8). In addition, Black and Hispanic caregivers are much more likely to provide high levels of care, with close to half of them providing more than 60 hours a month compared to 31 percent for White caregivers, as shown in Figure 9. Consequently, Black and Hispanic caregivers are much more likely to be working part-time or have dropped out of the labor force despite being younger, which substantially impacts their lifetime earnings and their own financial security in retirement (see Figure 10). Interestingly, over 40 percent of caregivers incurred out-of-pocket costs for caregiving. The share was fairly consistent across race/ethnicity (see Figure 11). This pattern could explain why direct payment policies are the top choice across all groups.

Tables 9-12 provide more detail about the various caregiving challenges facing different sociodemographic groups. Over 40 percent of all caregivers incurred out-of-pocket costs, but most of that burden falls on caregivers who provide more than 20 hours of care per month. Spouse caregivers are also much more likely to incur out-of-pocket caregiving costs compared to other types of caregivers (e.g. children or other relative). Children are also more likely to pay out-of-pocket for caregiving compared to other non-spousal relatives (see Table 9).

Caregiving can also have a large financial impact on caregivers because it requires them to drop out of the labor force or reduce their hours. Interestingly, while the descriptive statistics show that Black and Hispanic caregivers are much more likely to work part-time, narrowing the focus to workers only and controlling for other caregiving characteristics – such as the amount of care provided, whether they are the sole caregivers, and their relationship with the care recipient – shows that the racial/ethnic differences mostly disappear. The one exception is that Hispanic caregivers are still much more likely to work part-time (less likely to work full-time) if they provide more than 60 hours of care a month (see Table 10). Interestingly, working caregivers who are the sole caretakers and those caring for older adults with two or more activities of daily living (ADLs) are less likely to work part-time, perhaps because they need the resources to provide for the care. Similarly, children who are caregivers are also less likely to work part-time, likely due to their own financial needs.

Another way being a caregiver can have a financial impact is if the caregiver drops out of the labor force all together. Black and Hispanic caregivers are more likely to drop out than their White counterparts – a result largely driven by caregivers who provide more than 60 hours of care a month (see Table 11). Recall Figure 9 shows that Blacks and Hispanics are much more likely to provide 60+ hours of care relative to their White counterparts. However, after controlling for caregiver characteristics, Black caregivers are even more likely to drop out of the labor force relative to their Hispanic or White counterparts. One potential explanation may be that Black caregivers are less likely to have flexible hours, making it harder for them to balance caregiving and work. However, our analysis did not find such evidence (see Figure 12).

Finally, the analysis provides some back-of-the-envelope calculations to estimate the financial benefit of the policies discussed that are meant to help caregivers and see whether the financial value compares to focus group respondents' discussions. A brief summary of assumptions underlying these calculations is outlined below:

Paid Family Leave (PFL) or Paid Sick Leave. Typically, PFL or similar programs pay workers who have to take a temporary leave to care for someone with a serious illness. It pays workers a percentage of their average weekly pay for a certain number of weeks.[7] For state programs, the amount of wages replaced and how long workers get the payments vary substantially. The example used in the back-of-the-envelope calculation assumes caregivers receive 60 percent of the wages for 12 weeks and earn the average wage in 2022 of $63,795. If the caregiver receives 60 percent of the average wage for 3 months, the value of PFL is $9,569 a year. The theoretical lifetime value could be much higher since, technically, employees are eligible for the program every calendar year. However, it may be unlikely for workers to stay at the same employer if they are taking leave every year. Additionally, this policy would not provide any benefit for caregivers who were already retired or had dropped out of the labor force.

Direct Payment for Providing Family Caregiving. Some states have programs that pay family members a certain dollar amount for providing care.[8] The regression analysis shows that

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[7] U.S. Department of Labor (2024).

[8] Medicaidlongtermcare.org. (2024)

caregivers do not change their labor force decisions unless they are providing more than 60 hours of care per month. The assumption for this calculation is that such a caregiver is paid $15/hr. On average, family caregivers provide 74 hours of care a month, which would result in a payment of $11,000 per year. Since individuals on average provide care for 6.9 years, a lifetime value of this policy equates to almost $76,000. Black and Hispanic caregivers generally provide more hours of care (91 and 112 hours, respectively) over a longer period of time (7.1 and 7.3 years, respectively). The annual value of this policy is almost $14,400 for Blacks and $17,800 for Hispanic caregivers. The lifetime value is $102,500 for Blacks and $129,700 for Hispanics.

Tax Credit for Caregiving. The most relevant tax credit for family members providing care for an older adult is the Credit for Other Dependents, which provides a credit of up to $500 for dependents of any age.[9] The lifetime value of this credit is only around $3,500 for most family caregivers.

Social Security Caregiver Credit Act. Proposals for a caregiver credit towards Social Security typically involve replacing a person's missing earnings with a credit equal to half of the average wage index (AWI) for up to five years.[10] Once they retire, their benefit will be slightly higher because they will have fewer zero years in their earnings history. This difference in annual benefits for receiving a credit for up to five years is $1,172 a year, assuming caregivers claim at age 65. The average age of caregivers is 53, with an average life expectancy of 28 years. But since caregivers will not receive this higher value in Social Security benefits until they claim, value has to be discounted back to age 53 at a discount rate of 3 percent, resulting value of about $10,700. The value for Black and Hispanic caregivers is lower, roughly $8,400 and $10,350 respectively, because they become caregivers at younger ages and will have to wait longer to receive Social Security. The value of this credit is slightly higher for White caregivers – approx. $11,250. In addition to not providing immediate financial relief to caregivers, this policy also would not benefit caregivers with more than 35 years of earnings because lower or zero earning years outside of the highest 35 are already excluded. The policy also would not benefit caregivers who are already retired.

Paid Respite Care. The policy would pay for a limited amount of respite care so

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[9] While the amount of the credit is far less than the CDCTC, it is not restricted to expenses incurred by the caregiver to go to work, look for work, or attend school.

[10] U.S. Congress, S.1211 (2023).

caregivers could have a little break. If one day of paid respite care was provided per month, the annual value of this policy would be $1,140 for adult day care and $2,484 for a home health aide.[11] The lifetime value is approximately $7,870 for adult day care and $17,140 for a home health aide.

Reimbursements for Out-of-Pocket Care. Reimbursements could cover costs such as adding a ramp to the home, building a first-floor bedroom, modifying a car, etc. Most of these costs are not covered by insurance. Data from the NHATS/NSOC show that average out-of-pocket costs are around $980 annually for caregivers who incur costs. The lifetime value of this policy is $6,764.

Figure 12 compares the potential financial value of the various policies for family caregivers. Being paid directly for providing care offers the highest financial value for caregivers. Therefore, it is not surprising that it is one of the favorites among caregivers in our focus groups. Paid respite care, the third most popular policy among participants, provides the second highest financial value. Interestingly, while having out-of-pocket costs reimbursed ranked highly among focus group participants, but the actual financial value of this policy is relatively low. But the financial relief is immediate, which many participants valued. And many participants expressed that, despite the challenges, they valued the opportunity to care for their parents or spouse. Therefore, policies that allow them to not be a caregiver may also be of less value. These quantitative results help highlight why direct payments or reimbursements were so popular among focus group participants, particularly those from diverse backgrounds.

Conclusion

The focus group discussions showed that the policy perceived to make the most significant difference for caregivers was direct monetary compensation from the government, either by being paid for caregiving or through reimbursements for out-of-pocket costs. Conversely, the policy perceived as least beneficial was paid family leave or expanded sick leave. The responses align with the quantitative analysis, which shows that caregivers, particularly those from diverse backgrounds, incurred out-of-pocket costs for providing care and many had to cut back on work or leave the labor force altogether.

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[11] Data from Genworth shows that the median price for adult day care is $95/day and a home health aide is $207/day.

Overall, these results provide valuable insights for policymakers on the most effective interventions for alleviating the financial burdens associated with caregiving. Thus far, much of the policy discussion has focused on forms of paid leave, however, this policy is one of the least popular. Future research could examine the effectiveness of direct payments in alleviating financial hardship among caregivers.

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Table 1. *Caregiver Support Policies Discussed with Focus Group Participants*

Policy	**Policy Description**
A) Having paid family and medical leave or expanded paid sick leave	*This program usually pays workers who have to leave their jobs temporarily to care for someone with a serious illness. It pays people a percentage, for example, 60% of their wages, for a set period of time, such as around 12 weeks or three months.*
B) Being paid directly by the government for providing family caregiving services to an older adult for a certain amount of time	*The idea here is that if you provide these services, you will be compensated for them directly for a limited duration.*
C) Getting a tax credit on your income taxes for providing caregiving services to an older adult	*The idea here is that you would get some financial credit for being a caregiver by having the taxes that you pay on your income be lowered by a certain amount.*
D) Getting a "caregiver credit" toward earning Social Security benefits	*To receive Social Security when you retire, you have to pay Social Security taxes for at least 40 quarters or 10 years. The more quarters you work, the higher your Social Security benefits will be when you retire or become disabled. One policy proposal is to give people credits towards their Social Security benefits if they serve as caregivers of dependent individuals, even if they cannot work or cannot work full time. Caregivers can earn such credits for up to five years of service. When you retire, your Social Security benefits will be higher.*
E) Having respite care paid for	*The idea is that the government would support you by paying for you to have respite care. That is, you could organize either paid home care services for the people you care for or even care in a short-term residential setting for a certain amount of time so that you take time off from your care giving.*
F) Getting certain costs that you have to pay for and that are related to caregiving reimbursed	*These might include adding a ramp to a home, building out a first-floor bedroom to be fully accessible, modifying a car to accommodate a wheelchair, and other assistive devices (like special bathroom changes, ramps, etc.). The idea here would be that you could cover some or all of these costs if you paid for them as part of your role as a caregiver.*

Table 2. *Selected Sociodemographic Characteristics of the Study Sample (N=25)*

Measure	*M*	*SD*
Age	50.3	9.9
Gender		
Male	20%	
Female	80%	
Race/Ethnicity		
White	44%	
African American	40%	
Hispanic or Latinx	8%	
Pacific Islander or Native Hawaiian	4%	
Asian	4%	
Employment		
Currently employed full-time or part-time (including self-employed)	60%	
Retired or partially retired	20%	
Full-time homemaker or not employed outside the home	20%	
Income		
$75,000+	48%	
Below $75,000	52%	
Primary or Shared Caregiving		
Primary	64%	
Shared	36%	

Source: Focus group responses (N=25).

Table 3. *Select Participant Responses to Paid Family and Medical Leave (FMLA) or Expanded Paid Sick Leave*

Benefits
I have used FMLA when my mother had hip replacement surgery. [It was] extremely useful because I could get paid, and she was living in a different state, so it saved my job, and I could get paid while caring for her.
When my mom first had her first heart surgery, I never used it because I was working remotely during COVID and had a better balance. I think it's beneficial assuming you're employed out of the home. I want to say it's temporary, though, or there is a time limit.
I'm not working, but I'm sure it would be helpful for anybody working outside of the home. It'll be helpful for my sister.
Challenges and Concerns
[It] may save your job, but it only pays you for the time you have, like saved PTO time so I would not get paid once I use those days.
I don't work because I’ve cared for [my husband] for eight years. There was a time when he first got sick and was on FMLA but as soon as the 90-day limit hit, boom, he was fired. When you have someone that's disabled, they're disabled 365 days a year, it doesn't go away so there has to be some form of protection for working people to take paid family leave or medical leave without, saying, you exhausted this and we don't need you anymore.
I am self-employed, so I don't know if that would benefit me.
My schedule's flexible so I take time I need and work when I can. I don't have sick time or a medical leave kind of situation. I work for myself and the more I work the more I can make.
It needs to be all inclusive, whether you are working or not.. otherwise it means nothing.
It will benefit those who work outside of the home but there needs to not be a cap on it.

Table 4. *Select Participant Responses to Direct Payment for Family Caregiving Services*

Benefits
We don't have unlimited funding here, but while mom was sick, it would've helped.
Yes, it would be most helpful because being paid directly would help immediately. [My mother] needs immediate help and monetary support immediately rather than in a credit.
It would help in so many ways. It would take the burden off having to depend on my sons to take care of things when I have to work.
Challenges/Concerns
Direct payment for any amount of time would be helpful but the amount of time is the issue. Of course, any money to pay for family caregiving is wonderful, but disability is forever, [it's] for life.
It would help if it doesn't take 60 or 70 days or 80 days to get on it.
My county has a program where they do that. The only problem as some have mentioned, is that it's a very long approval process, maybe four to six months and the person you care for has to receive state-funded Medicaid, which my mom does not. So, for me it's not helpful.
Depends on where it is. In my state it's very helpful, but my family is based in another state and need people to come in urgently but don't have it. Like you have people from your family, they offer to come in and subsidize it and don't offer it throughout all the states and they should.

Table 5. *Tax Credit for Caregiving Services*

Benefits
We don't work here. It would help others going through that, but [not] for us.
It would benefit [my neighbor's] daughter. Her daughter does work, so it would be somewhat helpful, but not as helpful as being paid directly for a caregiver.
Challenges/Concerns
Direct payment for any amount of time would be helpful but the amount of time is the issue. Of course, any money to pay for family caregiving is wonderful, but disability is forever, [it's] for life.
It would help if it doesn't take 60 or 70 days or 80 days to get on it.

Table 6. *Select Participant Responses to Social Security Caregiver Credit Act*

Perceived Benefits
I haven't worked for several years because of caregiving, and it would be wonderful if that would help my Social Security go up because I haven't worked and only get my Social Security, which is low, so if my caregiving added to that, that would be great.
I agree with a caregiver credit toward earnings because when I quit working my earnings stopped so when I retire, it'll be based on my previous work history, and I won't have an opportunity to earn more. Whatever I earned 10 years ago, that's what I'll get. I'm pretty much dead in the water.
It sounds like it would benefit people who cannot get a job out of the home. I don't know how that would be calculated, but that sounds beneficial.
I think it might [help]. The only reason I say that is because we need money now so it would be beneficial, of course, if you had a credit or something and that percentage that we normally pay in from our Social Security would still count because if not, what will we fall back on?
Challenges and Concerns
I'm not [going to] retire for another 20 years, so I'd rather have money now. I don't like a promise for tomorrow.
I'd rather have the money to help us now than when I'm old enough to retire or not have to work if I could. There's so much we need now than later.
I guess eventually it would work if it’s not so much red tape to get the benefits.
I think you should get your credit or your monthly check and then that percentage also goes to Social Security.

Table 7. *Select Participant Responses to Paid Respite Care*

Perceived Benefits
Time management is such a huge thing, and I believe it would benefit both the caregiver and the person cared for. Sometimes separation is not bad.
Towards the end, we had to take respite care. It gave us a five-day break to make plans because we knew at that point [my mother] was only given a week to live. It helped us out a lot. They could take care of her a lot better than we were.
I would find it helpful if it covered the cost for my mom to go to some kind of day program for a few hours. I'd love something like that for her to leave the home if that could be paid for.
It'd be very nice to have the time not to worry about being here and taking care of things so I could go and do what I want.
Yeah. I think, daycare... when it works, it works. It gives us a break. It allows my dad to get out and be in a different atmosphere.
Challenges and Concerns
One of the challenges is that options are limited. I don't trust many people and would want to have a preferred vendor or caregiver, like family or someone we know. Sometimes, when they provide a service like this, they contract with only certain vendors under certain eligibility requirements. So, having more options for families to choose from would be something that would benefit that policy.
If you're going to send somebody in that's not me, they would need body armor and be willing to defend themselves aggressively. I don't know if it would be safe for them, but I would like the option to have it and then if we don't use it we could use the money otherwise.
I don't see how that would help because the main thing we're trying to do is keep her from being put in a nursing facility or somewhere. We've had a lot of problems with the care she's gotten in different places, and I don't feel like that would fix our problem.
I don't think it would be helpful. My husband would not want someone coming here to do what I've been doing, and it would be just more of an aggravation.

Table 8. *Select Participant Responses to Reimbursement Caregiving-Related Costs*

Perceived Benefits
It would be very helpful. Since coming home with the ambulance and the wheelchair, we don't have ramps and it's very difficult. I don't have a shower downstairs, which complicates it. And, I don't have a seat to get them upstairs. So we started trying, I am looking for that and I have not found anything that would be helpful, but it would be very, very helpful.
Anything we can do to reduce cost [is] going to be great.
We had to pay for our ramps with her not being able to walk, we had no choice. We had to get the ramps in, and they said it could take a year or so to get your insurance to pay for it. We went ahead and just paid for it. We had no choice, but we could find somebody who would come out and do it for just cost, of the supplies so that helped us a lot. But waiting a year to build a ramp when your mom doesn't have a year to live is difficult.
We have a savings account that's set up to accommodate my husband for the bathroom. We have a ramp on the front porch, so that's extremely helpful so I can at least get him out. But as far as the bathroom, it's very expensive, and you have to do it. So if a program reimbursed some of those costs, that would be very helpful.
There's a lot of things insurance doesn't cover. With adjustable beds, ramps, we had to get a lift. We had to buy a customized van too for the lift. Something as minor as a shower chair, it's $60. But when you talk about all the other medical supplies, you have to have your pocket open for the course of a month, and it gets very costly.
We had to pay for expenses like some accommodations for a bathroom so my mom could use it and the shower more easily. It would be helpful if those could be paid back.
Right now, probably, yes. Any reimbursed cost would.
Yes, I think that would help. We could do many things in the house that would make caring for her much easier if we could afford it, but we're just not.
Challenges and Concerns
It's not something that would benefit my situation, but I see how it would help families based on the supply and need.
Unless it's a large cost that had to happen and a large reimbursement, which we haven't had to do so far, like it'd almost be too much trouble to have to go through the process to get the reimbursement.
It could take a year or so to get your insurance to pay for it.

Table 9. *Probability of Caregivers Incurring Out-of-Pocket Costs Providing Care*

	(1)	(2)
Race of caregiver		
Non-Hispanic Black	0.0343	-0.00147
	(0.0335)	(0.0570)
Hispanic	0.0361	0.121
	(0.0375)	(0.0681)
Work status		
Not employed - not retired		-0.0622
		(0.0359)
Employed - FT		0.0511
		(0.0367)
Employed - PT		0.0289
		(0.0390)
Level of caregiving		
20-60 hours/month		0.114***
		(0.0332)
60+ hours/month		0.202***
		(0.0357)
Level of caregiving # race		
Non-Hispanic Black # 20-60 hours/month		0.0940
		(0.0830)
Non-Hispanic Black # 60+ hours/month		0.0980
		(0.0747)
Hispanic # 20-60 hours/month		-0.129
		(0.0939)
Hispanic # 60+ hours/month		-0.227**
		(0.0861)
Sole caregiver		0.0305
		(0.0259)
Age		-0.00275*
		(0.00109)
Care recipient has 2+ADLs		-0.0109
		(0.0243)
Spouse		0.724***
		(0.0456)
Child		0.132***
		(0.0286)
Constant	0.409***	0.277***
	(0.0148)	(0.0722)
Observations	1,588	1,467
R-squared	0.001	0.212

Note: Standard errors in parentheses: *p <0.05, ** p <0.01, *** p< 0.001.
Source: Authors' calculations.

Table 10. *Probability of Caregiver Working Part-Time, among Workers*

	(1)	(2)
Race of caregiver		
Non-Hispanic Black	0.0802	0.0414
	(0.0420)	(0.0741)
Hispanic	0.0956*	-0.0000350
	(0.0465)	(0.0864)
Level of caregiving		
20-60 hours/month		-0.0257
		(0.0412)
60+ hours/month		-0.0162
		(0.0494)
Level of caregiving # race		
Non-Hispanic Black # 20-60 hours/month		-0.0324
		(0.108)
Non-Hispanic Black # 60+ hours/month		0.101
		(0.0992)
Hispanic # 20-60 hours/month		0.195
		(0.117)
Hispanic # 60+ hours/month		0.223*
		(0.113)
Sole caregiver		-0.115***
		(0.0346)
Age		0.00657***
		(0.00138)
Care recipient has 2+ADLs		-0.128***
		(0.0310)
Spouse		-0.0536
		(0.0886)
Child		-0.269***
		(0.0370)
Constant	0.302***	0.253***
	(0.0191)	(0.0702)
Observations	886	877
R-squared	0.007	0.109

Note: Standard errors in parentheses: *p <0.05, ** p <0.01, *** p< 0.001.
Source: Authors' calculations.

Table 11. *Probability of Caregivers Being Out of the Labor Force but Not Retired*

	(1)	(2)
Race of caregiver		
Non-Hispanic Black	0.0619*	0.132*
	(0.0275)	(0.0511)
Hispanic	0.0791*	0.0843
	(0.0308)	(0.0623)
Level of caregiving		
20-60 hours/month		0.0570
		(0.0294)
60+ hours/month		0.158***
		(0.0305)
Level of caregiving # race		
Non-Hispanic Black # 20-60 hours/month		-0.0926
		(0.0743)
Non-Hispanic Black # 60+ hours/month		-0.160*
		(0.0664)
Hispanic # 20-60 hours/month		-0.0389
		(0.0847)
Hispanic # 60+ hours/month		-0.0419
		(0.0779)
Sole caregiver		-0.0386
		(0.0228)
Age		-0.000717
		(0.000887)
Care recipient has 2+ADLs		-0.0137
		(0.0214)
Spouse		0.0557
		(0.0413)
Child		-0.0179
		(0.0247)
Constant	0.191***	0.190***
	(0.0122)	(0.0491)
Observations	1,601	1,569
R-squared	0.006	0.030

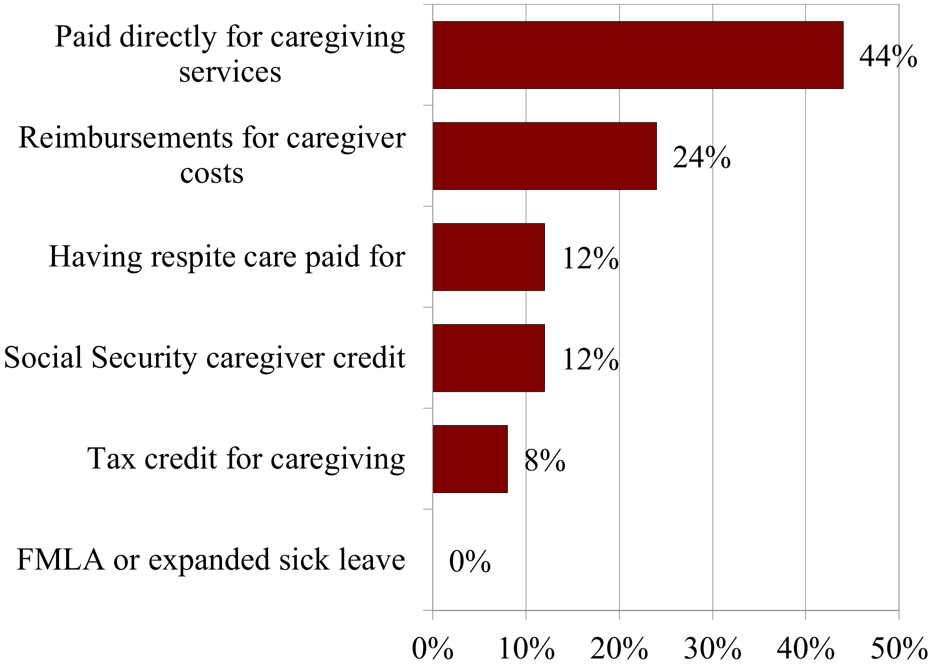
Note: Standard errors in parentheses: *p <0.05, ** p <0.01, *** p< 0.001.
Source: Authors' calculations.

Table 12. *Probability of Caregivers Having Flexible Hours, among Workers*

	(1)	(2)	(3)
Race of caregiver			
Non-Hispanic Black	-0.0946*	-0.0701	-0.129
	(0.0433)	(0.0449)	(0.0828)
Hispanic	-0.0440	-0.00815	0.127
	(0.0477)	(0.0496)	(0.0936)
Work Status			
Not employed - not retired			
Employed - FT			
Employed - PT		-0.143***	-0.144***
		(0.0355)	(0.0378)
Level of caregiving			
20-60 hours/month			0.0637
			(0.0472)
60+ hours/month			0.00765
			(0.0605)
Level of caregiving # race			
Non-Hispanic Black # 20-60 hours/month			0.0764
			(0.120)
Non-Hispanic Black # 60+ hours/month			0.0866
			(0.114)
Hispanic # 20-60 hours/month			-0.322*
			(0.130)
Hispanic # 60+ hours/month			-0.153
			(0.126)
Sole caregiver			0.00865
			(0.0400)
Age			-0.0000697
			(0.00159)
Care recipient has 2+ADLs			-0.0218
			(0.0364)
Spouse			0.215*
			(0.0990)
Child			0.0106
			(0.0437)
Constant	0.408***	0.464***	0.440***
	(0.0197)	(0.0246)	(0.0807)
Observations	890	795	786
R-squared	0.006	0.024	0.043

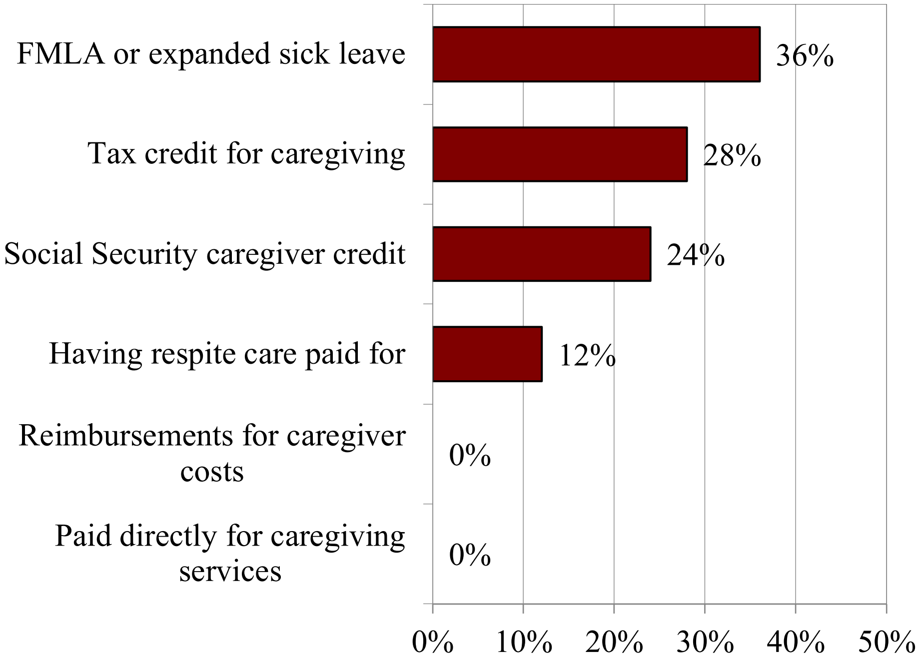
Note: Standard errors in parentheses: *p <0.05, ** p <0.01, *** p< 0.001.
Source: Authors' calculations.

Figure 1. *Most Important Caregiver Support Policies*



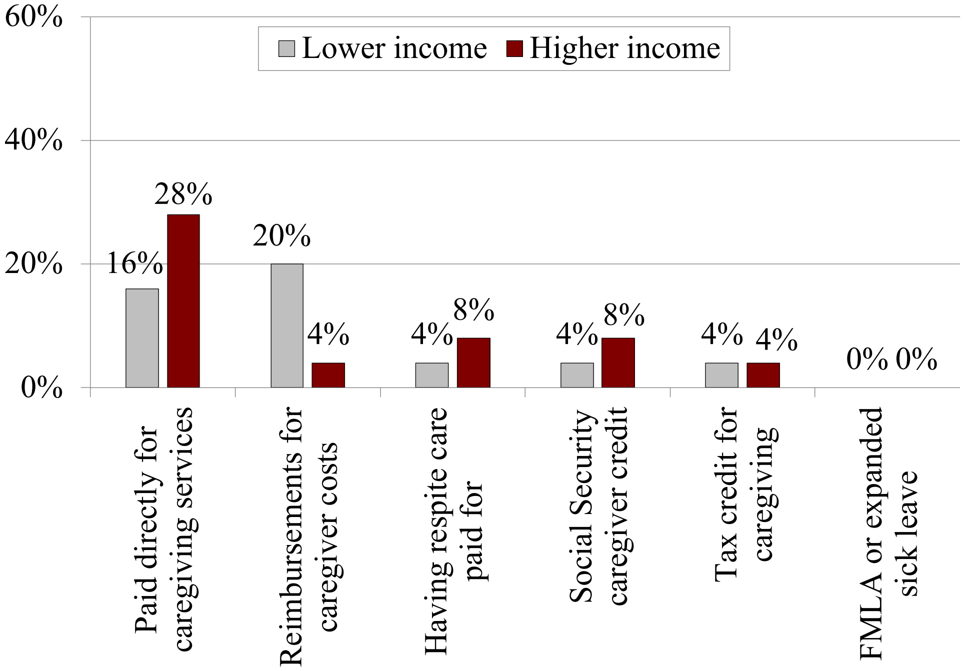
Source: Focus group responses (N=25).

Figure 2. *Least Important Caregiver Support Policies*



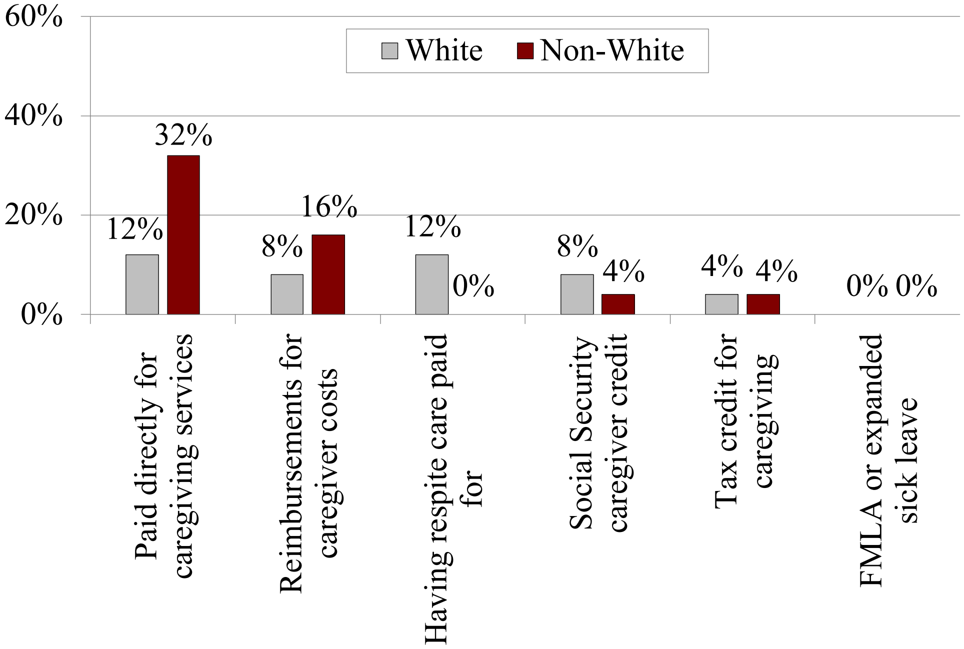
Source: Focus group responses (N=25).

Figure 3. *Distribution of Most Preferred Policy, by Income*



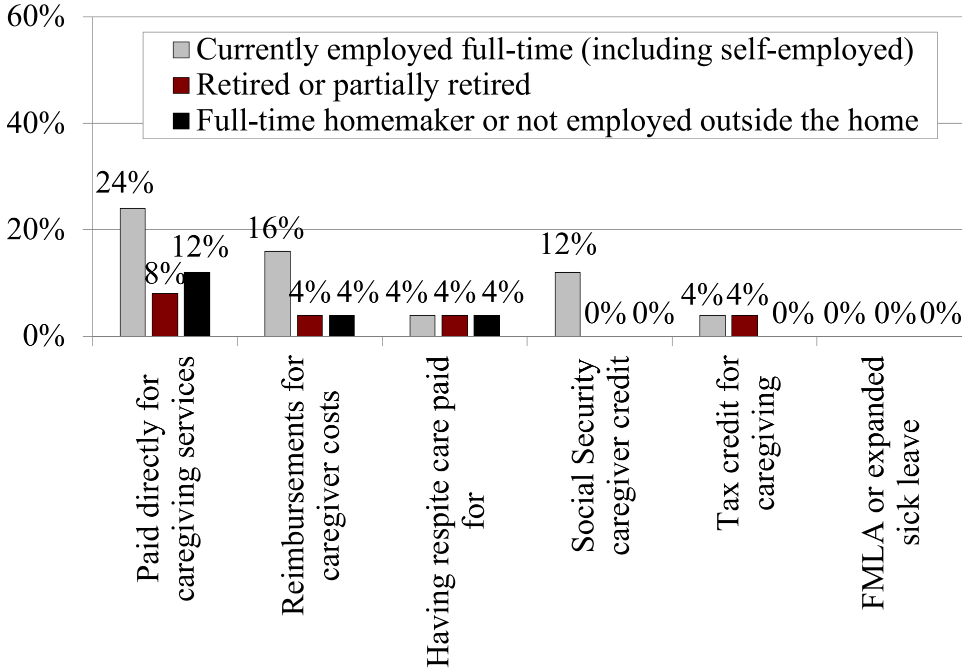
Source: Focus group responses (N=25).

Figure 4. *Distribution of Most Preferred Policy, by Race*



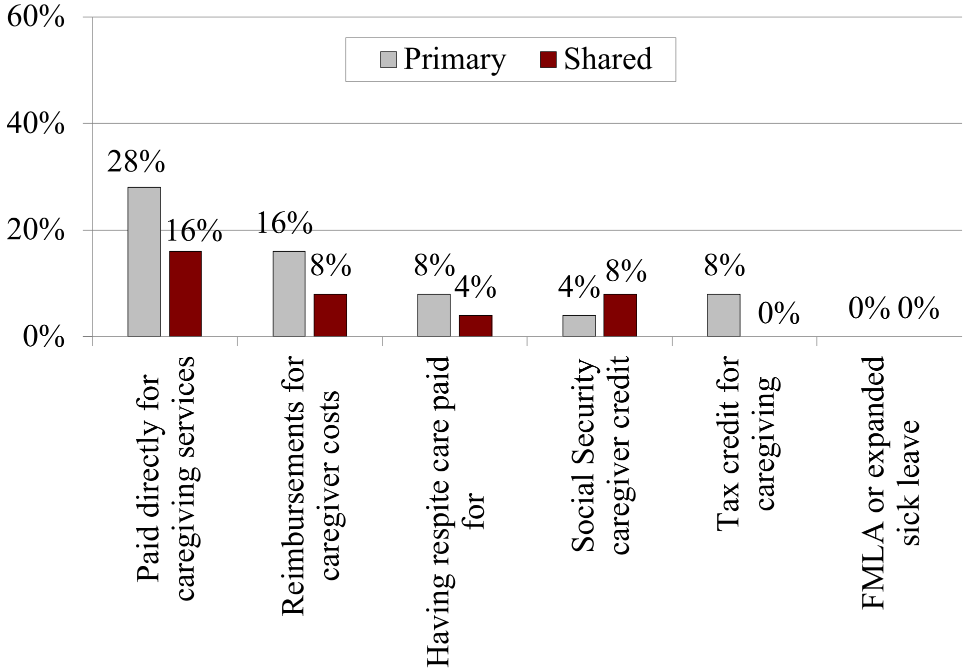
Source: Focus group responses (N=25).

Figure 5. *Distribution of Most Preferred Policy, by Employment Status*



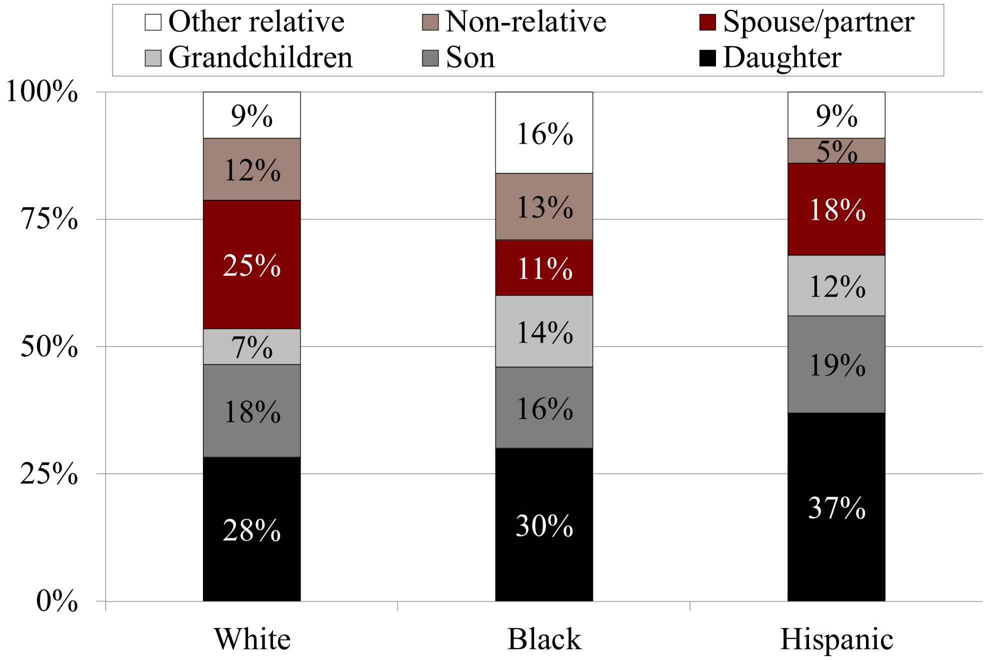
Source: Focus group responses (N=25).

Figure 6. *Distribution of Most Preferred Policy, by Caregiver Status*



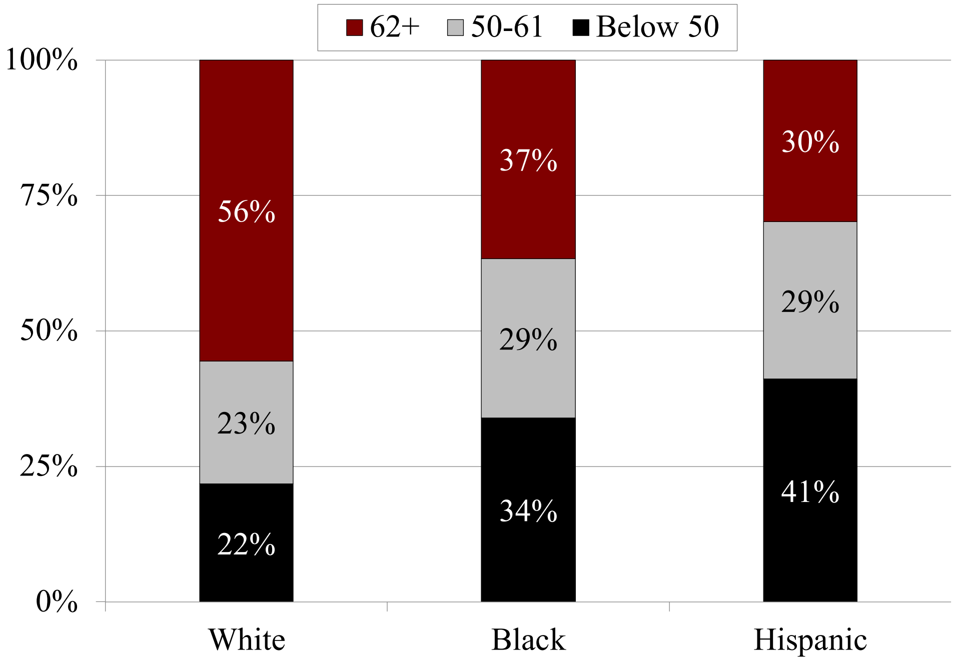
Source: Focus group responses (N=25).

Figure 7. *Caregiver Relationship to Care Recipient, by Race/Ethnicity*



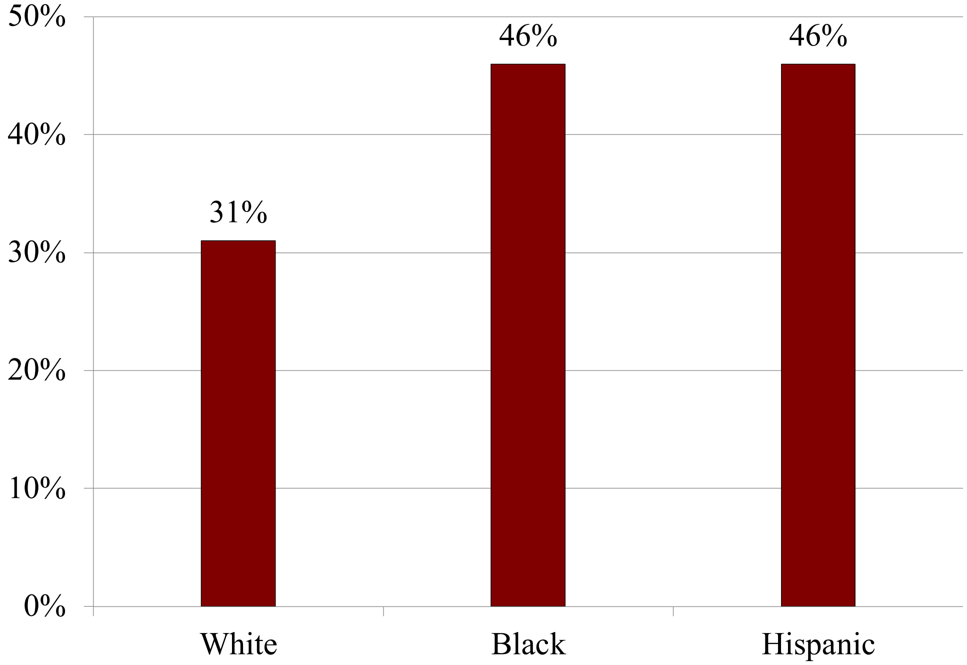
Sources: Authors' calculations using *National Health and Aging Trends Study* (NHATs) and *National Study of Caregiving* (NSOC) (2021-2022).

Figure 8. *Distribution of Age of Family Caregivers, by Race/Ethnicity*



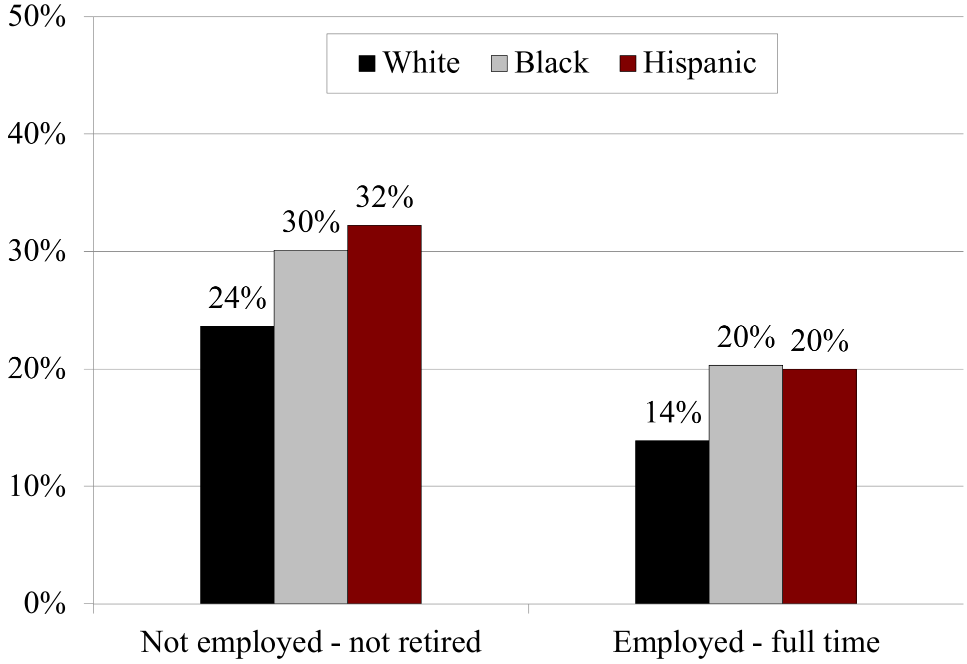
Sources: Authors' calculations using NHATs and NSOC (2021-2022).

Figure 9. *Share of Family Caregivers Providing 60+ Hours of Care Per Week, by Race/Ethnicity*



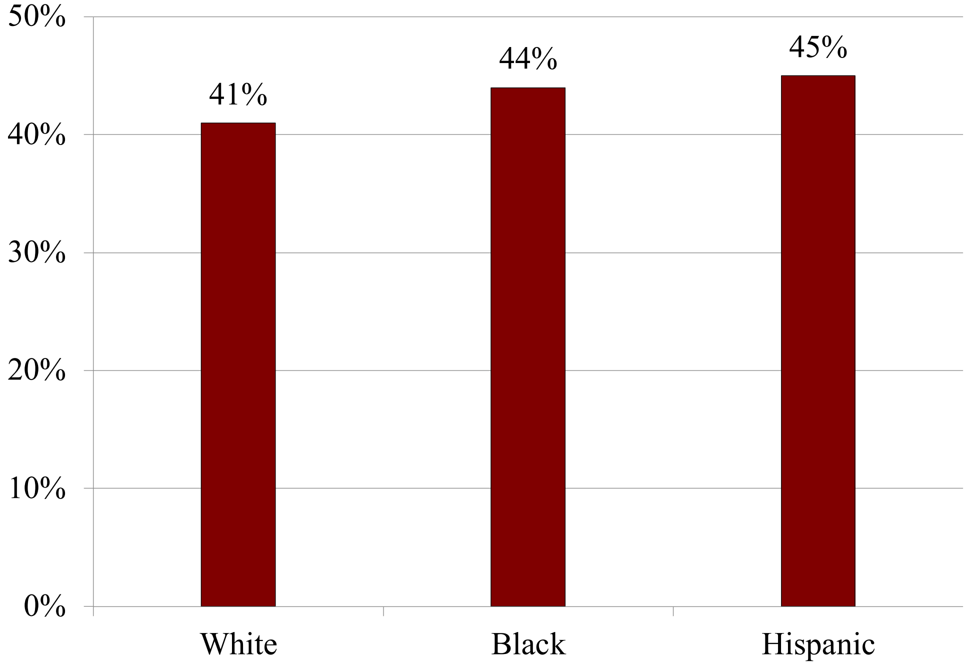
Sources: Authors' calculations using NHATs and NSOC (2021-2022).

Figure 10. *Share of Family Caregivers Not Employed and Not Retired vs. Employed Full-Time, by Race/Ethnicity*



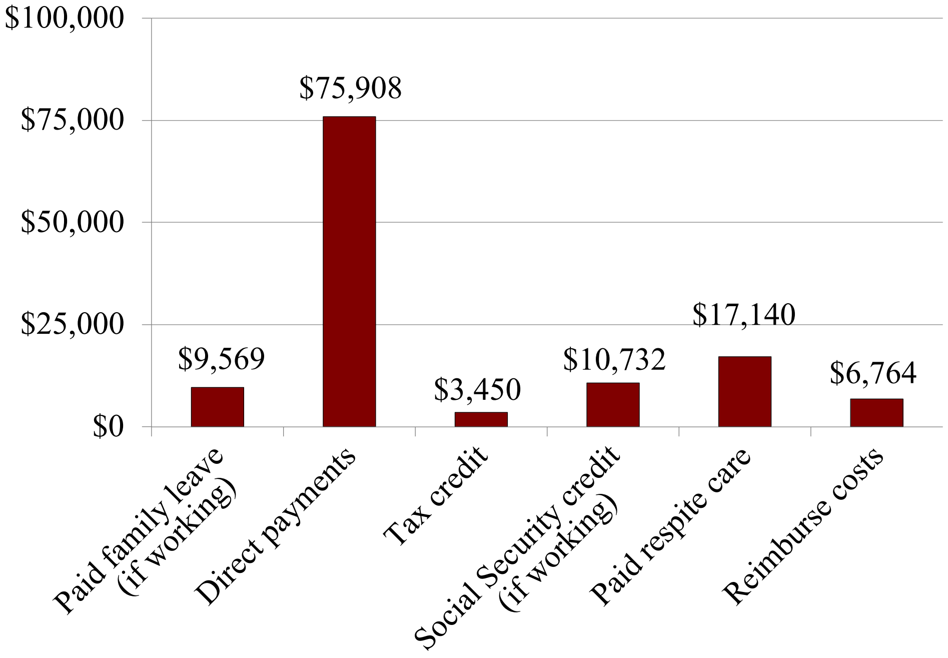
Sources: Authors' calculations using NHATs and NSOC (2021-2022).

Figure 11. *Share of Family Caregivers Facing Out-of-Pocket Expenses for Caregiving*



Sources: Authors' calculations using NHATs and NSOC (2021-2022).

Figure 12. *Back-of-the-Envelope Estimates of the Financial Value of Various Caregiving Policies*



Note: For those not working/retired, paid family leave and the Social Security credit would have no value.
Source: Authors' calculations.

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