

## Spotlight Article

# Addressing the Diverse Needs of Unpaid Caregivers Through New Health-Care Policy Opportunities

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About 41 million spouses, children, and other relatives have provided unpaid care to a family member aged 50 years or older in the past 12 months (AARP, 2020). Population aging is increasing demand for these unpaid caregivers, who play a valuable role in allowing older adults to age in place. Longer lifespans have increased the number of Americans living with health conditions such as Alzheimer's disease and dementia, which require extended periods of intensive care. Whereas care for aging Americans was traditionally shouldered by adult daughters, daughters-in-law, and wives, trends in family structure and employment and growing racial/ethnic diversity have altered who provides care, the type of care provided, and potentially their beliefs about caregiving. There has been some growth in policies and programs supporting family caregivers, but they have not kept up with the realities of caregiving for many Americans. Studies have reported on state and federal policies that address some previously unmet needs, such as paid and unpaid family leave and financial support to caregivers (Dawson et al., 2020); however, this patchwork of policies only addresses some groups of an increasingly diverse set of caregivers. For example, the Older American Act (OAA) of 1965, the first to bring social services to older persons living in the community, is a grant-based program with disparate access to services depending where one lives (Administration for Community Living, 2020). Despite the growing numbers of unpaid caregivers providing an array

of care services with disparate support needs, they remain invisible in the health-care system that relies on them to provide this care. In this article, we first describe the caregiving landscape in the U.S. population today. Next, we highlight opportunities within the current health-care system: in particular, those with the potential to address some unmet needs of modern caregivers. Finally, we suggest avenues for future research to inform policy.

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## Caregiver Diversity

We described and quantified differences across caregivers, their tasks and strain, and their use of services, utilizing data from a survey of family members and other unpaid caregivers who assist older persons with disabilities: the 2017 National Study of Caregiving (Table 1). The comprehensiveness of these data provides a broader examination than is common in the extant literature. Caregivers were drawn from sample persons in the National Health and

**Table 1.** Diversity in Caregiver Demographics and Experiences From the National Study of Caregiving 2017

	%, Mean
<b>Caregiver demographics</b>	
Female, %	64.9
Race/ethnicity, %	
Non-Hispanic white	73.5
Non-Hispanic black	12.0
Non-Hispanic other	2.8
Hispanic	8.3
Missing	3.5
Age groups, %	
<40	8.3
40–49	10.3
50–59	25.0
60–69	25.0
70–79	17.9
80+	7.3
Missing	6.1
Relationship to care recipient, %	
Spouse/partner	20.6
Daughter	29.6
Son	16.6
Other relative	23.2
Neighbor/friend	8.3
Other nonrelative	1.7
<b>Caregiving duration and intensity</b>	
Provided care for more than 1 year, %	66.1
Number of hours per month, %	
<20 hours	32.5
20–39 hours	20.6
40–59 hours	10.7
60–79 hours	8.3
80–99 hours	6.6
100 + hours	21.2
Number of hours per month by recipient needs	
All caregivers	
Mean	72.5
Median	32
In last month of care recipient's life	
Mean	149.5
Median	90
Care recipient has probable/possible dementia	
Mean	84.5
Median	40
Caregiver provides help with ADLs most days	
Mean	177.4
Median	120
Care recipient has probable/possible dementia, %	31.1
<b>Caregiver experiences</b>	
Work status, % <sup>a</sup>	
Did not work last week	45.4
Retired	10.8
Missing	3.8
Worked for pay last week	40.0

**Table 1.** Continued

	%, Mean
<b>Distance to care recipient</b>	
Coresident, %	41.3
Lives near, %	47.7
Minutes away, mean	15.2
Lives far, %	6.3
Hours away, mean	3.9
Missing/did not help in last month, %	4.7
<b>Support and services, % yes</b>	
Friends/family help with care recipient	59.8
Used [respite] service to take time away, last year	12.2
Went to support group, last year	3.1
Received training from medical providers, last month	16.2
<b>Caregiver strain, % yes</b>	
Financial difficulty helping	15.2
Emotional difficulty helping	41.5
Physical difficulty helping	19.0
<b>Type of care provided</b>	
<b>Health care–related tasks, % yes</b>	
Ever help order meds	35.8
Keep track of meds	45.8
Help administer shots/injections	7.6
Manage medical tasks	8.1
Help with skin care/wounds	20.4
Help with exercises	25.9
Help with special diet	25.2
<b>Help with personal care (i.e., ADLs), % yes</b>	
Everyday/most days	18.0
Some days	20.1
Rarely/never	61.9
<b>Help with chores, % yes</b>	
Everyday/most days	40.4
Some days	24.9
Rarely/never	34.7
<b>Shopped for care recipient, % yes</b>	
Everyday/most days	29.1
Some days	40.3
Rarely/never	30.4
<b>Drove care recipient, % yes</b>	
Everyday/most days	18.9
Some days	36.9
Rarely/never	44.1

*Note.* All estimates weighted to be population representative. Dementia ascertainment based on National Health and Aging Trends Study algorithm. Total number of observations = 2652. Helped last month, sample person alive ( $n = 2324$ ); helped last month of life, sample person deceased ( $n = 288$ ); or did not help last month ( $n = 40$ ). ADLs = activities of daily living.

<sup>a</sup>Among caregivers not caring in last month of life.

Aging Trends Study who reported receiving care from a family member or other unpaid caregiver. When weighted, estimates from respondents in both surveys are designed to be nationally representative of persons 65 years and

older and their caregivers (Freedman et al., 2020). About 65% of caregivers were female and 23% of caregivers were nonwhite. Cultural and gender expectations about caregiving and familial responsibility may affect caregiving decisions and the perceived burden of providing care. Daughters served as caregivers more frequently than sons (30% vs. 17%, respectively). Spouses (21%) and other relatives (23%) were also common caregivers. About 10% of unpaid caregivers, however, were not related. Half of caregivers were aged 60 years or older. About 40% of caregivers were working for pay. Adult children who are caregivers may be balancing careers and caregiving, and some may be simultaneously caring for their children. While older caregivers are more likely to be retired than younger caregivers, they are more likely to have health conditions requiring care themselves.

Where caregivers and the persons they care for live, and the distance between them, can also have important implications for the types of care they provide, the caregiving support they need, and their access to support and services. Most caregivers co-resided (41%) or lived nearby (48%) the care recipient, but others traveled several hours to provide care (6%). Most caregivers reported financial, emotional, and or physical difficulty with caregiving (76%), yet few accessed services like respite care (12%) or support groups (3%), though it is unclear whether this is due to their preferences for these programs or lack of access.

Care may be episodic or long-term; over 66% of respondents provided care for more than one year. About 33% of caregivers provided less than 20 hours of help a month, while nearly 28% of caregivers provided 80 or more hours. The needs of care recipients shift over time and differ depending on the type of illness. Care after a hospitalization may require short-term 24-hour care, while caring for persons with dementia often grows in intensity over time. Caregivers helping with personal care (e.g., eating, bathing) most days provided, on average, 177 hours of assistance a month. Care in the last month of life was also taxing; the average number of hours a caregiver provided in the last month of a care recipient's life was 150, compared to an average of 73 hours.

The challenges caregivers face may also vary by the types of care they provide and the severity of the physical, mental, cognitive, or functional limitations of the care recipient. Caregiver responsibilities and tasks included driving (56%) and daily assistance with eating and bathing (18%). About two in five caregivers provided help with personal care, such as dressing or bathing. The most common assistance caregivers performed was help with chores (40%) and health care–related tasks, such as keeping track of medications (46%). Almost a third of caregivers cared for someone with probable or possible dementia. Caregivers for persons living with dementia generally had a higher prevalence of depression than caregivers for persons without dementia

(Chen et al., 2020). Despite limited training from medical providers (16%), caregivers also helped with administering shots (8%), helped with wounds (20%), and managed medical tasks (8%).

The vast differences in who provides care, their relationships to care recipients, the type of care they provide, and whether they are employed, among the many other dimensions described here, beg the question of how national policies can be designed and implemented to address their diverse needs. The next section highlights recent policies and programs within the health-care system that are beginning to help caregivers and notes where there is opportunity to expand on these programs to better serve caregivers in America today.

### Health-Care Policy Opportunities

There are opportunities within the current health-care system to engage family and other unpaid caregivers, support end-of-life care, provide long-term supports and services, and better utilize technology. Each of these programs has the potential to be leveraged or expanded to improve the well-being of caregivers and their care recipients.

One step toward engaging family caregivers is the Recognize, Assist, Include, Support, and Engage (RAISE) Family Care Act of 2018. The act created a Family Caregiving Advisory Council that reflects the diversity of family caregivers (Cacchione, 2019). The council will provide recommendations on best practices for supporting family caregivers: for example, Medicare and Medicaid reimbursement to physicians for health assessment of caregivers. Additionally, policymakers in 40 states enacted Caregiver Advise, Record, Enable (CARE) acts, which formally document caregivers in the patient's record and require hospitals to provide caregivers with the date of discharge and instructions for care after discharge (Dawson et al., 2020). These policies are important for helping caregivers who perform health care–related tasks, such as managing medications (46%), specialized diets (25%), or exercises (26%). Although both of these policies are largely symbolic in nature, they are steps forward, as they begin to recognize the importance of integrating family members and other unpaid caregivers as part of the care team and to acknowledge the diversity of caregivers. Recommendations for improving caregivers' access to supportive services that were generated as part of the RAISE Family Care Act could inform future programs funded through the OAA, while evidence of CARE acts' success in reducing rehospitalization would validate the benefit of this policy for all 50 states.

Care at the end of a loved ones' life can be difficult and time intensive, with caregivers spending up to 3 times as many hours in the last month of life compared to the average caregiver. Comprehensive palliative care, concurrent hospice and treatment, and training can provide

needed support for family and friends caring for loved ones at the end of their life. However, hospice care is designed around conditions with short time horizons for the end of life and an agreement to forgo curative disease treatment, making it unsuitable for those with conditions that may benefit from concurrent treatment and palliative care (Meier et al., 2017). The Centers for Medicare and Medicaid Services (CMS) recently announced a new demonstration project, beginning in 2021, to test coverage of hospice and palliative care through Medicare Advantage plans, allowing plans to offer palliative care, transitional concurrent care, and hospice benefits. Palliative care has been shown to reduce the caregiver burden (Meier et al., 2017). Assessing how and for whom this coverage adds value provides new opportunities to improve outcomes for patients and their caregivers.

Unpaid caregivers provide the majority of long-term services and supports (LTSS), in part because long-term services are expensive and not covered by Medicare (Doty & Spillman, 2015). LTSS are covered by Medicaid but only for those who are income eligible. Long-term care insurance is available, but barriers to it are well documented and only about 14% of those 60 years and older have policies (Brown & Finkelstein, 2007). With many ineligible or unable to afford formal LTSS, the burden falls to unpaid family and other caregivers to provide care. Attempts to implement a national insurance program for LTSS have failed; however, the state of Washington enacted the Long-Term Care Trust Act, which is the first state-run long-term care insurance program. Another advance, the Creating High-Quality Results and Outcomes Necessary to Improve Chronic Care Act of 2017, allows Medicare Advantage plans to pay for LTSS, although access will vary because companies can determine whether to provide services and which services to provide. Enhanced access to formal LTSS may help ease the burden on family and other unpaid caregivers by allowing those with the greatest needs to get formal help.

Technological innovations have the potential to expand access to care and reduce strains on family and other unpaid caregivers. In response to the coronavirus disease 2019 pandemic, the CMS temporarily expanded reimbursement for telehealth to all beneficiaries and has proposed changes to expand telehealth permanently. Telehealth allows long-distance caregivers to join appointments remotely and provides access to health care for those in rural areas or without transportation available. For example, three National Institute on Aging-funded pilot programs—Care Ecosystem, Tele-Savvy, and Moving Together—are attempting to reach persons living with dementia and their caregivers living in communities that lack access to specialized dementia care and support (NIA, 2020). These programs support both the dementia patient, by helping create care plans, and the caregivers through online caregiver education and exercise programs. Initial

evidence indicates the Care Ecosystem's dementia care services reduced the caregiver burden and rates of caregiver depression and decreased the number of emergency department visits (Possin et al., 2019). Yet, lack of quality Internet service may impede utilization and reduce the effectiveness of telehealth. In 2018, 26% of Medicare beneficiaries lacked any digital access at home and 41% lacked access to a computer with high-speed Internet (Roberts & Mehrotra, 2020).

New technologies such as remote activity monitoring also have the potential to support caregivers by providing real-time monitoring and a sense of security when they are unable to be there. In small-scale studies these solutions have shown promise, but more research is required to understand their utility (Mitchell et al., 2020). These technological innovations have the potential to allow caregivers to balance work and caregiving because they can monitor their loved ones from afar and even participate in medical appointments.

## Conclusions

Long-term services and support for the growing number of older persons in the United States draws on a cadre of family and other unpaid caregivers. Socioeconomic, demographic, and health shifts in the population are reshaping who provides care and care needs. We highlighted several opportunities within the health-care system to improve support for caregivers. However, a patchwork of federal, state, and local policies and programs that do not address the diverse needs of caregivers remains. Systematic evaluation of policies and programs is lacking, leaving gaps in our understanding of what works, for whom, and under what circumstances. Future research evaluating the effectiveness of these policies and whether they improve well-being among caregivers and care recipients is a critical next step to understanding and addressing the diversity of their needs.

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## Conflict of Interest

None reported.

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