A Serial Cross-Sectional Study of Older Adult Caregivers in the United States from 1997 to 2019

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Abstract

Background: There is a current and projected discrepancy between the number of older adults requiring care in the United States and the number of health care professionals available to provide that care. This incongruity may shift care responsibilities onto informal, non-professional, and unpaid caregivers — a population that is itself aging. Although international research exists on older adult caregivers, there is a need to explore the U.S.-specific older adult caregiver (OAC, ≥ 64 years old) experience, given this country's distinct values, culture, and policies surrounding aging and caregiving. This study investigates the demographics and descriptive context of OACs from 1997 to 2019 in the U.S., as well as compares and contrasts OACs with caregivers < 64 years old in 2019.

Methods: Repeated, cross-sectional study using secondary data from national surveys. Participants include 153, 156, 385, 529, and 537 U.S. OACs in 1997, 2004, 2009, 2014, and 2019 respectively, Statistical tests used: Jonckheere-Terpstra (J-T) and Cochran-Armitage tests for trend, chi-square tests of independence, and the Mann-Whitney U-test.

Results: In 1997, the median age of U.S. OACs was 70.0 years old, which rose to 73.0 in 2019. The percentage of OACs grew each year, with OACs being 10–13% of the respondents in 1997 and 2004 to roughly 30% in 2014 and 2019. OACs became more diverse in terms of race and sexual orientation, and more balanced in terms of sex, income, and education. The majority identify their health as good/very good, and most do not think caregiving has impacted their health. The median length of time caregiving decreased from 3 to 2 years from 1997 to 2019. Significant differences were found between OACs versus caregivers < 64 years old in 2019 in the number of instrumental activities of daily life performed; choice to become a caregiver; type of caregiver they are; if they needed more information managing their own stress; and if they had plans in place for their own future care.

Conclusion: The role of OAC is becoming an increasingly new and shared experience among a more varied group of individuals in the U.S. than previously. Recommendations based on these results include screening patients ≥ 64 years old by a primary care provider (PCP) to determine if a patient identifies as a caregiver or is performing common caregiver duties. Earlier detection of caregiving status could lead to earlier interventions. Additional research should investigate the unique needs and circumstances of OACs in order to provide targeted interventions to improve their lives and the lives of their care recipients.

Introduction

Census data projects that by 2030, 1 in 5 Americans will be over the age of 64, with that estimate increasing to 1 in 4 by 2060 (1, 2). Although COVID-19 mortality rates disproportionately impacted those over the age of 64 (3), it has yet to be determined if or how this will impact mid-century population estimates; thus, it is reasonable to maintain that the U.S. population as a whole will increase in age over the next several decades. However, the U.S. population is not only aging but also undergoing other demographic changes. Additional population level projections include: greater gains in life expectancy for men than women; a longer life expectancy for foreign-born versus native-born individuals, regardless of race; and an increase in the number of the very oldest, those over 84 years old — nearly doubling by 2035, and nearly tripling by 2060 to 19 million (1, 2). The U.S. Census projects that by 2060, the average 65-year-old man or woman could expect to have 21 to 24 more years of life (1).

Meanwhile, the number of practicing geriatric health care professionals (e.g., physicians, physician assistants, registered nurses) is not keeping pace

Methods

This study employed a repeated cross-sectional design using survey data collected in 1997, 2004, 2009, 2014, and 2019 on behalf of the National Alliance for Caregiving (NAC). Surveys were randomly administered to selected U.S. households via phone and online and conducted in English and Spanish. Deidentified survey data was downloaded from the NAC website, and codebooks to explain the data's nomenclature were also included (25). Codebooks explaining the data's nomenclature were included with these data sets.

Criteria for this study for all 5 years included: 1) identifications as a caregiver, 2) fully completed survey, and 3) age ≥ 64. A fourth criterion to include caregivers age 18–63 was only applied to the 2019 survey for age comparison analyses.

Demographic variables include OACs' age, sex, race, sexual orientation, household income, education, and location. Contextual variables studied were CRs' age and sex (note: CRs' race was not collected in any survey); number of CRs per OAC; relationship of OAC to CR; primary illness of CR; current health status; impact of caregiving on one's health; length of time caregiving; number of tasks completed, categorized as ADLs and instrumental activities of daily living (IADLs); OAC employment status; whether the caregiver felt they had a choice in taking on their responsibilities; needing more information to manage one's emotional/physical stress; type of caregiver (e.g., sole, primary but not sole); if the caregiver had plans in place for their own future care; and weekly hours spent caregiving.

This study used IBM SPSS Statistics 29.0.2.0, Microsoft Excel 16.78.3, GraphPad Prism 10.4.0, and GraphPad QuickCalcs. A non-parametric, independent-sample Jonckheere-Terpstra test evaluated for numeric trends over time. The Cochran-Armitage test looked at categorical trends over time. Chi-square tests of independence analyzed categorical variables and the Mann-Whitney U-test evaluated variable medians. Responses recorded as unknown, refused, and/or do not know, and were <2% of the total responses, they were omitted from analysis. All statistical significance tests used a significance level (alpha) of 0.05 (5%). The Geisinger Institutional Review Board reviewed and determined this study not subject to oversight (#2022-0708).

Results

Sample sizes of OACs were 153, 156, 385, 529, and 537 for 1997, 2004, 2009, 2014, and 2019, respectively. In 1997, the median age of OACs was 70.0 years old, which rose to 73.0 in 2019, seen in Figure 1. The maximum age for an OAC in these surveys was 99 years old, occurring 6 times in 2004 and once in 2019. The median age of the oldest OACs (≥ 80 years old) was 81.0 in 1997 and 83.0 in 2019.

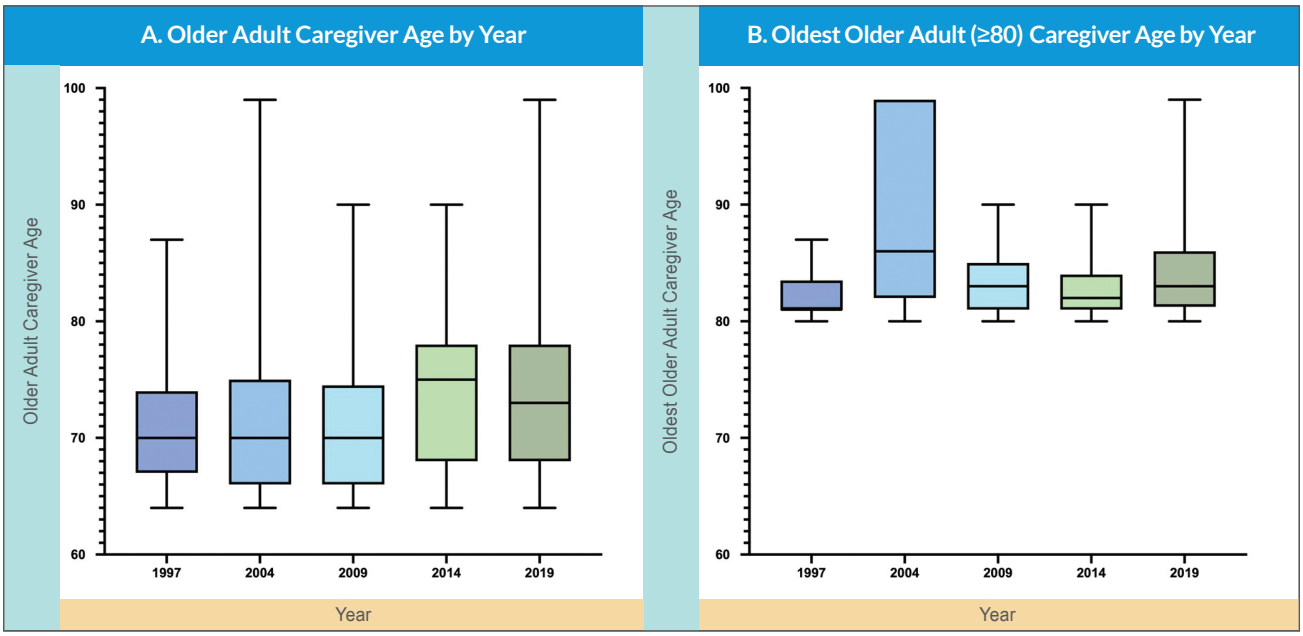

Figure 1. Median age and age range of older adult caregivers (≥ 64 years old) and oldest adult caregivers (≥ 80 years old). Boxes represent interquartile ranges, horizontal lines within boxes are median ages, and the extending bars display the minimum and maximum ages.

with this demographic change (4–7). This shortage of geriatric-focused professionals is unlikely to be reconciled by 2030 (8). Research has found that older adults are more likely to have chronic health conditions and comorbidities, and thus, utilize the health system more than other age groups (1, 9–11). Importantly, audits of nursing homes, which are often permanent or stopgap residences for older adults, find inadequate numbers of staffing to provide quality care to patients (12). This imbalance in supply and demand creates a void in older adult patient care — a void that is very likely to shift responsibility onto informal, non-professional, and unpaid caregivers — a population that itself is aging.

Much of the literature on the current state of caregiving within the United States investigates the definition, identification, and burden of caregiving (13–15). Also common is research on caregivers who are specifically identified through the lens of the care recipient's (CR) disease or disability (e.g., caregivers for patients with dementia). (16, 17) A 2019 systematic review on the health of caregivers who care for older adults emphasized the necessity for additional research, targeted interventions, and long-term study of *caregiver subgroups* to potentially counter the idea that caregiving leads to "negative health outcomes" (18). These caregiver subgroups could be defined by intrinsic independent variables (e.g., race or sex) to investigate for similarities and differences, but given the aging U.S. population and likely future shift toward informal, non-paid caregiving as previously mentioned, caregiver age — and older age specifically — seems especially timely and necessary.

Outside of the U.S., researchers have been investigating the older adult caregiver (OAC) subgroup. In Taiwan, a study found OACs used more home services for their care recipients' (CRs) activities of daily living (ADLs) than younger caregivers. (19) Receiving extra assistance with nursing care — changing catheters, drawing blood — resulted in significant improvement in the OACs' self-reported health (19). Additionally, older CRs self-reported better health if their caregiver was also older (19).

Another Taiwanese study assessed caregiver burden of OACs using the Neuropsychiatric Inventory Questionnaire (NPI-Q) and shortened Zarit Burden Interview (20). Lower income, more functional impairment of CRs' ADLs, and higher severity in CRs irritability and apathy were all independent predictors of increased OAC burden (20). Caregiver age was another independent predictor but with an inverse correlation to burden of caregiving (20). A 2021 Italian investigation used the Caregiver Burden Inventory (CBI) and found that physical burden of caregiving had a significant sex difference with females reporting worse physical health than males (21). OACs also experienced a moderate burden on their time and schedule (21).

A 2020 Swedish study of OACs found an association between caregiving and low mental "health-related quality of life" (22). Factors most associated with low quality of life for caregivers were low financial status, low cognitive ability (based on mini-mental state estimation (MMSE)), and worry about one's own health (22).

A longitudinal Swedish study compared functional, physical, and mental health of OACs to older non-caregivers at baseline and after 6 years (23). Researchers created 4 tracks based on status (e.g., track 1: caregiver at baseline/caregiver at follow-up), and found high turnover rates in caregiver status after 6 years. Older age correlated with poorer functional, physical, and mental health in all tracks. In contrast to the other studies, no correlation was found between OAC health and low financial status nor gender (23).

These international studies highlight the differences within and between caregiver age groups; however, literature on OACs remains limited (19–21). Few contributions explore the American OACs experience, even though the U.S. has unique cultural norms and public policies regarding caregiving and aging than other countries. This study aims to rectify this gap in knowledge, promote visibility for the OAC subgroup, and provide useful data for designing possible solution to improve OAC health outcomes, which has been shown to positively impact CR health (24).

The hypothesis and specific aims were to evaluate if median OAC age in the U.S. shows a significant increasing trend over time from 1997 to 2019. Additionally, isolate OAC demographics from 1997 to 2019 and highlight any changes. Next, provide descriptive context about OACs and CRs from 1997 to 2019. Lastly, compare a subset of those contextual variables between OACs and younger caregiver (<63 years) in 2019 hypothesizing a significant difference between groups.

A J-T test of median age did not show a statistically significant trend for either group — neither those ≥ 64 years old (p=.166) nor those ≥ 80 years old (p=.801). However, the percentage of OACs completing surveys grew each year with OACs being 10–13% of the respondents in 1997 and 2004 to roughly 30% in 2014 and 2019, as shown in Table 1. There was also growth among the oldest OACs from 9% in 1997 to 19% in 2019.

Additional OAC demographics from 1997 to 2019 are shown in Table 1. Sex distribution of OACs became more balanced over time. In 1997, OACs were only 24.2% male, but in 2019 were 43.0%. White, non-Hispanic OACs remained the majority across the years. Those identifying as "Asian, Pacific Islander, non-Hispanic OACs" or as "Other" saw increases from 5.9% to 11.5% and 0% to 4.8%, respectively, from 1997 to 2019. In that same time, OACs identifying as "Black, non-Hispanic" and as "Hispanic" decreased from 21.6% to 8.2% and 11.1% to 7.4%, respectively. In 2014 and 2019, 3.8% and 4.3% of OACs identified as lesbian, gay, bisexual, and/or transgender (LGBT). Other demographic changes include a shift from OAC households being majority low-income (<$50k) to more equal distribution across incomes; more OACs reaching a post-high school education; and an increasing majority of OACs living in non-rural areas.

The maximum age of CRs in each of the survey years was 97, 97, 99, 107, and 103 years old respectively, provided in Appendix Table 1, which shows characteristics of the CRs. In 2014, there were two 100-year-olds, five 101-year-olds, and one 107-year-old CRs, and in 2019, there were five 100-year-olds, one 101-year-old, four 102-year-olds, and two 103-year-olds CRs. OACs for these centenarians ranged from 65 to 81 years old in 2014 and 68 to 80 years old in 2019. In 2009, 4.7% of OACs cared for someone under 18 years old, while only 2% did in 2019. The 3 other surveys excluded caregivers of those < 18 years old. A chi-square test of independence found a statistically significant relationship

	1997	2004	2009	2014	2019
Responses, No. (0%)	153 (10.1)	156 (12.5)	385 (21.8)	529 (33.8)	537 (30.9)
Age range, y	64 — 87	64 — 99	64 — 90	64 — 90	64 — 99
Median age, y (IQR)	70 (67-74)	70 (66-75)	70 (66-74)	75 (68-78)	73 (68-78)
Age ≥ 80 years, No. (%)	13 (8.5)	23 (14.7)	55 (14.3)	99 (18.7)	100 (18.6)
Sex[a] No. (%)					
Male	37 (24.2)	60 (38.5)	126 (32.7)	222 (42.0)	231 (43.0)
Female	116 (75.8)	96 (61.5)	259 (67.3)	307 (58.0)	306 (57.0)
Race, No. (%)					
White, non-Hispanic	94 (61.4)	96 (61.5)	244 (63.4)	399 (75.4)	365 (68.0)
Black, non-Hispanic	33 (21.6)	17 (10.9)	56 (14.5)	40 (7.6)	44 (8.2)
Asian, Pacific Islander, non-Hispanic	9 (5.9)	21 (13.5)	36 (9.4)	35 (6.6)	62 (11.5)
Hispanic	17 (11.1)	20 (12.8)	44 (11.4)	44 (8.3)	40 (7.4)
Other	0 (0)	2 (1.3)	5 (1.3)	11 (2.1)	26 (4.8)
Identify as LGBT[b], No. %					
Yes	-	-	-	20 (3.8)	23 (4.3)
No	-	-	-	483 (91.3)	478 (89.0)
Refused/No response recorded	-	-	-	26 (4.9)	36 (6.7)
Income, No. (%), $					
< $50k	129 (84.3)	88 (56.4)	200 (51.9)	244 (46.1)	183 (34.1)
$50k - $100k	6 (3.9)	30 (19.2)	113 (29.4)	190 (35.9)	197 (36.7)
> $100k	2 (1.3)	18 (11.5)	37 (9.6)	95 (18.0)	156 (29.1)
Unsure/Refused	16 (10.5)	20 (12.8)	35 (9.1)	0 (0)	1 (0.2)
Education, No. (%)					
Less than high school	36 (23.5)	9 (5.8)	30 (7.8)	28 (5.3)	20 (3.7)
High school grad/GED	53 (34.6)	47 (30.1)	90 (23.4)	137 (25.9)	113 (21.0)
Some college	28 (18.3)	38 (24.4)	110 (28.6)	107 (20.2)	116 (21.6)
Technical school, Associate's degree	8 (5.2)	6 (3.8)	11 (2.9)	40 (7.6)	55 (10.2)
College graduate, Bachelor's degree	17 (11.1)	33 (21 .2)	61 (15.8)	97 (18.3)	108 (20.1)
Graduate or Professional degree	10 (6.5)	21 (13.5)	83 (21.6)	120 (22.7)	125 (23.2)
Location[c] No. (%)					
Rural	-	40 (25.6)	107 (27.8)	98 (18.5)	73 (13.6)
Not Rural	-	113 (72.4)	268 (69.6)	430 (81.3)	462 (86.0)

Table 1. Characteristics of Older Adult Caregivers (OACs). Percentages may not equal 100% due to rounding. [a]In the 1997-2014 surveys, the only choices for caregiver sex were Male or Female. "Refused" was added to the 2019 survey, however no OAC selected that answer. [b]In the 1997-2009 surveys, no question was asked regarding a caregiver's sexual orientation or gender identity. In 2014, participants were asked if they identified as lesbian, gay, bisexual, or transgender (LGBT), and in 2019, the question more broadly asked if a participant identified as LGBT, other sexual orientation, and/or other gender identity. [c]In the 1997 survey, no question was asked regarding caregiver's location.

(χ^2=5.182, df=1, p=0.0228) in the number of CRs under and over 18 years old for 2009 versus 2019. Distribution of CR sex remained roughly 1/3 male to 2/3 female from 2009 to 2019.

The number of individuals cared for by OACs decreased over time. Most OACs had a single CR (1997, 76.5% and 2019, 81.4%) as shown in Appendix Table 2. The 3 most recent surveys found 7.5%, 4.2%, and 5.2% of OACs cared for both an adult and child.

Appendix Table 3 highlights all relationship types between OACs and CRs. The three most common relationships were "friend, neighbor, non-relative," "spouse," and "parent," which changed positions over the years. "Spouse" overtook "parent" for the top spot in 2014 (34.2%) and 2019 (27.7%), shown in Figure 2. Figure 3 highlights a CR's primary illness, with the 2 most common responses being "old age" and "Alzheimer's, confusion, dementia, forgetfulness," followed by "mobility," "surgery," "cancer," and "mental Illness" in varying positions over time.

When OACs rated their current health status, the responses "good" and "very good" were the top choices every year, shown in Figure 4A. "Poor" decreased from 5.77% in 2004 to 1.30% in 2019 and "excellent" also declined nearly 50% from 2004 to 2019. Figure 4B shows that most OACs felt caregiving did not affect their health from 2004 to 2019. The percentage of OACs who felt caregiving made their health better has declined since 2014. The 1997 survey did not ask either question about health status.

The median length of time an OAC spent caregiving was 3 years in 1997, 2004, and 2009, and 2 years in 2014 and 2019. There was no significant trend over time in the length of time spent caregiving (p=0.83). There was no significant trend in the sum of ADLs and IADLs completed by OACs across the 5 years (p=0.480). On average, OACs performed nearly twice as many more IADLs per day than ADLs, as shown in Figure 5.

A significant association was found between OACs who were never employed while caregiving and those who were (χ^2=36.39, df=1, p=<0.0001). In 1997, 35% of OACs were employed while caregiving, which decreased to 22% in 2019. No significant trend over time was found for whether OACs felt they had a choice in caregiving (yes/no) with responses roughly 50:50 each year (p=0.4204); and if OACs wanted more help with managing their own physical/emotional stress (yes/no) with the majority responding "no" each year (p=0.1318). The 1997 survey did not ask either question.

	Caregivers ≥ 64	Caregivers < 64
Did you feel like you had a choice in taking on care for this recipient / taking on this responsibility?* No. (%)		
Yes	267 (49.7)	526 (43.8)
No	270 (50.3)	671 (55.8)
Primary caregiver status*, No. (%)		
Sole caregiver	244 (45.4)	561 (46.7)
Primary but not sole caregiver	123 (22.9)	201 (16.7)
Someone else is the primary caregiver	115 (21.4)	286 (23.8)
Caregiving is shared equally	51 (9.50)	149 (12.4)
Do you need more information or help with managing your own emotional or physical stress?*, No. (%)		
Yes	109 (20.3)	354 (29.5)
No	426 (79.3)	834 (69.4)
Do you have plans for your own future care?*, No. (%)		
Yes	355 (66.1)	501 (41.7)
No	178 (33.2)	696 (57.9)
How would you describe your current state of health? No. (%)		
Excellent	52 (9.68)	117 (9.73)
Very good	176 (32.8)	374 (31.1)
Good	210 (39.1)	463 (38.5)
Fair	91 (17.0)	205 (17.1)
Poor	7 (1.30)	42 (3.49)
How has caregiving impacted your health? No. (%)		
Made it better	21 (3.91)	61 (5.07)
Not affected	405 (75.4)	848 (70.6)
Made it worse	110 (20.5)	289 (24.0)
Hours spent caregiving, No. (%)		
< 20 hours	349 (65.0)	792 (65.9)
≥ 20 hours	185 (34.5)	399 (33.2)

Table 2. Analysis of Older Adult Caregivers Versus Caregivers < 64 Years Old in 2019. Note: Percentages may not equal 100% due to rounding. *Indicates significant association found with p-values < 0.05.

For 2019, 1,739 responses by caregivers <64 years old were included. A significant difference was found in median number of IADLs performed by OACs versus younger caregivers (5 versus 4 respectively, U=297442, p=0.0082) but found no significant difference in median number of ADLs (p=0.9928) nor sum of ADLs and IADLs performed between groups

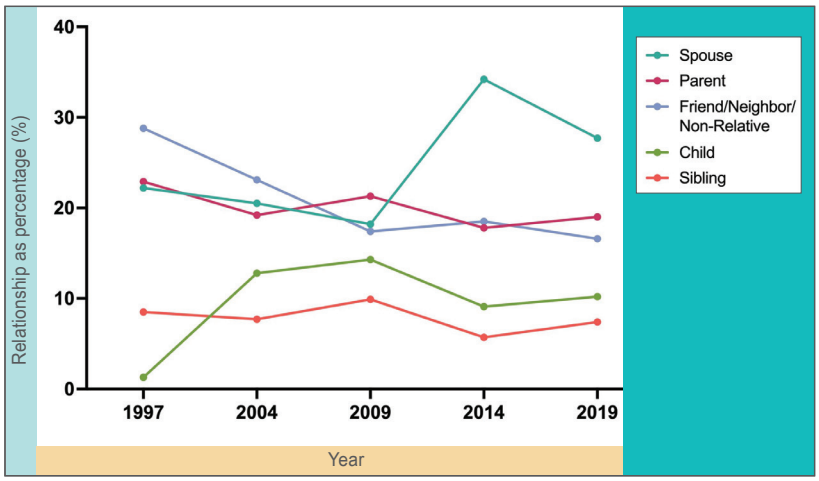

Figure 2. Top 5 relationships of older adult caregivers to their care recipient by year (i.e., "The care recipient is my…")

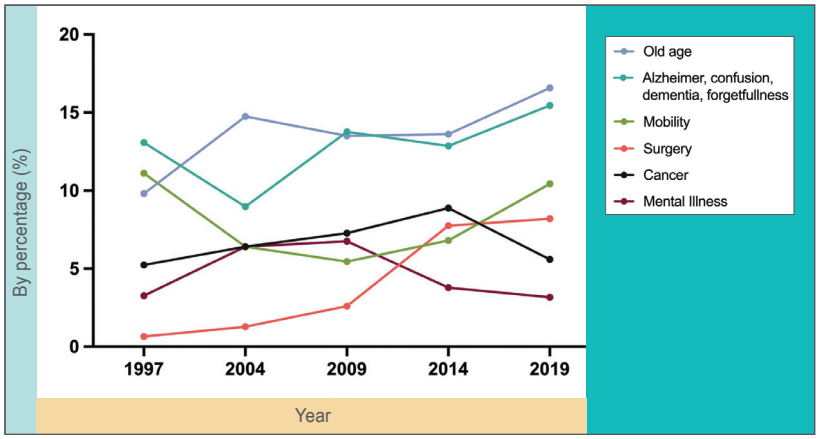

Figure 3. Primary illness of an older adult caregiver's care recipient by year

(p=0.1367). Shown in Table 2, significant associations were found between caregiver age group and these variables: whether the caregiver felt they had a choice in caregiving (χ^2=4.986, df=1, p=0.0256); the type of caregiver they are (χ^2 =12.14, df =4, p=0.0164); if they wanted help managing their emotional/physical stress (χ^2=16.67, df=1, p=<0.0001); and if plans were in place for their own future care (χ^2=90.37, df=1, p=<0.0001).

There was no significant association comparing caregivers by age group and the following variables: current health status (p=0.1536); the impact caregiving had on caregiver's self-reported health (p=0.1145); and the number of hours spent caregiving (<20 hours versus ≥ 20 hours) (p=0.6428), also shown in Table 2. There was no significant difference in median length of time caregiving for OACs versus younger caregivers (p=0.2495) with median length of time being 2 years for both.

The top 3 CR conditions, in descending order, for both OACs and younger caregivers were "old age," "Alzheimer's, confusion, dementia, forgetfulness," and "mobility" in 2019. For OACs, these were followed by "surgery" and "cancer." For the younger caregivers, "cancer" then "mental illness" rounded out the top 5.

Discussion

No significant trend found over time was found in the median age of OACs, as hypothesized, nor among the oldest OACs (≥ 80 years old). However, the percentage of OACs and oldest OACs grew each year, which is in concordance with U.S. Census population projections (1, 2). Sex distribution of OACs became increasingly even, possibly due to changing attitudes regarding stereotypical gender roles in the U.S., where women were assumed to take on the role of caregivers, as well as due to the greater projected life expectancy gains for men versus women. As more men live longer, they may find themselves becoming an OAC (1, 2).

Evolving demographics of OACs — more balanced in terms of sex, income, and education, and more diverse in race and sexual orientation — suggest that the OAC role is becoming a new shared experience among a more varied group of individuals in the U.S. With more people living this experience, it seems an opportune time for further OAC research. In light of these results, a recommended clinical application would be for PCPs would be to screen all patients ≥ 64 years old to determine if the patient identifies as an OAC or is performing common OAC responsibilities. Earlier detection of caregiving status could lead to earlier interventions such as connecting OACs with social workers, offering periods of respite, and emphasizing the need to prioritize self-care.

OACs care for a wide age range of CRs from children to centenarians, providing cross-generational care to parents, children, and sometimes, even grandchildren.

In 2019, many OACs (45%) identified as being the sole caregiver for their CRs, which is similar to younger caregivers (47%). Intergenerational caregiving may create unexpected and/or complex dynamics between families, e.g., an OAC may face legal barriers when acting as primary caregiver to their grandchild. This type of caregiving may also conflict with an OAC's sense of self, e.g., identifying as a daughter to then identifying as a caregiver to a parent. Chen et al. found that older CRs (≥ 65 years old) in Taiwan self-reported better health if their caregiver was also older. Research exploring inter- and intragenerational caregiving could elucidate if one has more favorable outcomes for OACs and/or CRs.

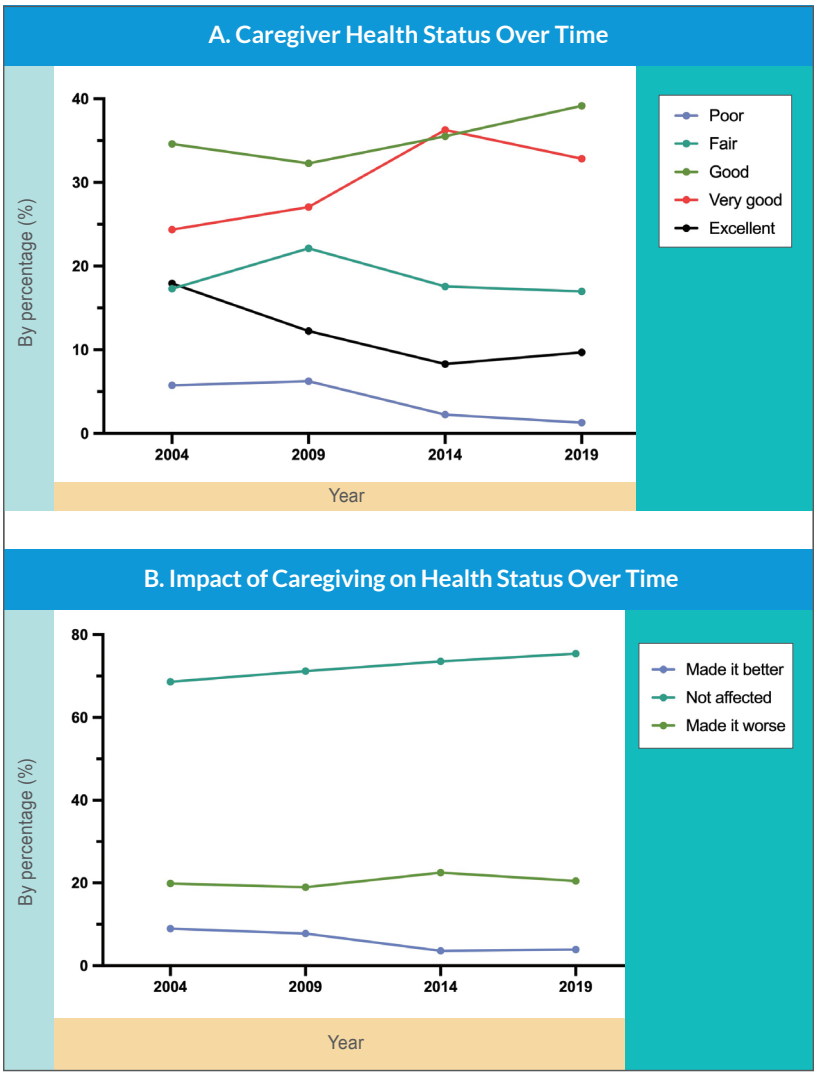

Figure 4. Current Self-reported Health Status and Impact of Caregiving on Health Status by Year. Note: Question was not asked in the 1997 survey.

The majority of OACs take care of 1 individual, which most recently is identified as the OACs' spouse. As more people require informal caregiving, OACs may have to choose who to help and opt to care for a spouse over less-intimate relations. Another plausible factor could be the recent cultural and legal shifts surrounding LGBT relationships. Perhaps in later surveys, LGBT caregivers felt more comfortable identifying their CRs as a same-sex spouse instead of referring to them as a non-relative. Further research on the LGBT-identifying caregiver subgroup could help elucidate this point.

Most CRs of OACs and of the younger caregivers in 2019 need caregiving due to "old age." More precise questioning regarding old age as a condition may differentiate not only why a CR requires care but also why an OAC does not. This may even help facilitate predictions as to when OACs would need future care themselves. One study contends it may not be the CR's specific illness/disability that correlates to caregiver burden, but rather the tasks associated with it (15). A possible intervention is for PCPs to inquire about ADLs/IADLs performed, instead of a CR's specific illness, and provide resources accordingly.

Studies have found contradicting results regarding caregiver burden and its impact on health (13–15, 18–21). In this study, OACs from 2004 to 2019 felt their health was unaffected by their role and rated their health as "good" or "very good" in those years. Individuals who are in good health may be more likely to become caregivers; these results may reflect selection bias (26). Similarly, due to social desirability bias, OACs may not report the negative impacts of caregiving. Without follow-up and independent verification, a self-reported status of "good health" or "no impact on health" will remain in question. Incorporating validated and commonly used tools within the surveys, such as the CBI, NPI-Q, and/or MMSE, would allow for better-quality comparisons and improved understanding regarding caregiver health and burden between studies.

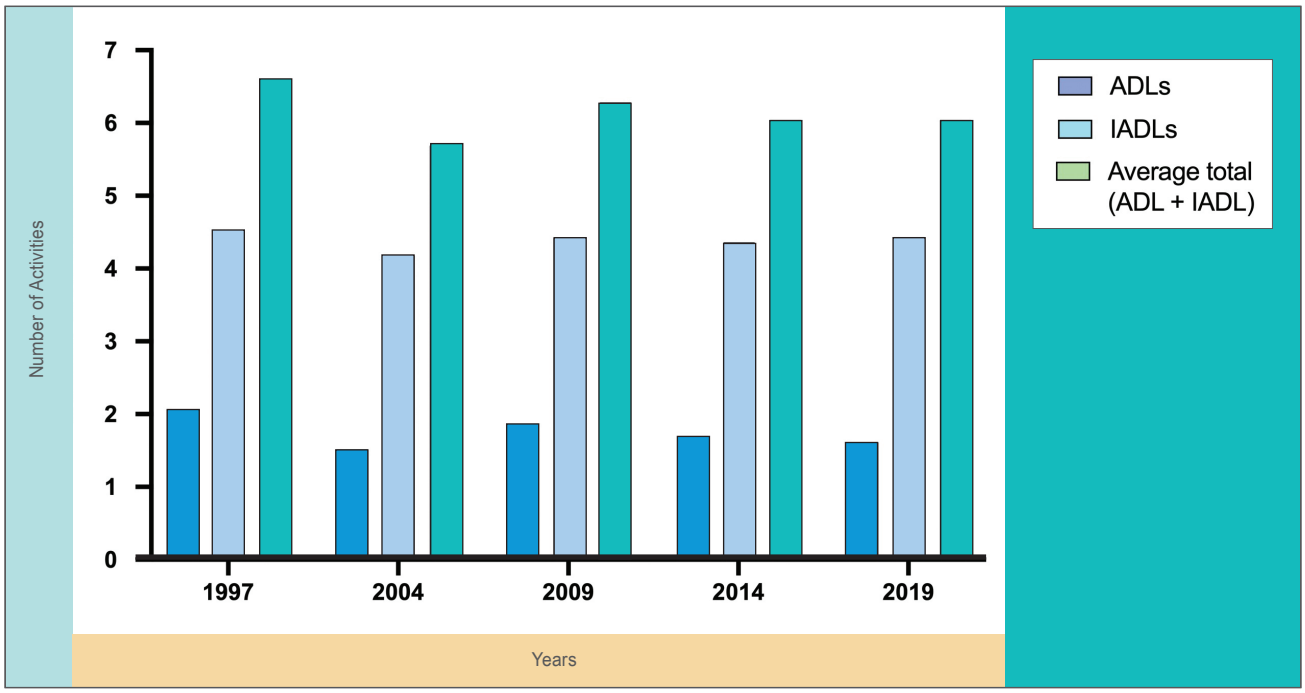

Figure 5: Average Number of Activities of Daily Life (ADLs) and Instrumental ADLs (IADLs) Performed by an Older Adult Caregiver by Year. Examples.of ADLs include feeding, bathing, dressing, and transferring CRs. IADLs include providing medical care, managing finances, arranging services, shopping and meal preparation, doing housework, and transporting CRs.

OACs spend 2–3 years caregiving, which is comparable to younger caregivers. One study found a high rate of turnover in caregiver status over 6 years and recommended routine and repeat screening of older patients' caregiver status. (23) That study also found that becoming a caregiver correlated to a positive impact on health (23), which suggests there may be a favorable time to identify, educate, and support OACs to potentially help mitigate any negative outcomes caused by caregiving.

Since 1997, OACs perform a 2:1 ratio of ADL:IADL tasks with an average of 6 tasks per day. ADLs include bathing, dressing, and transferring CRs. IADLs were defined as providing medical care (e.g., giving medications/injections), managing finances (e.g., paying bills, completing insurance claims), arranging services (e.g., home health aides, medical appointments), shopping and meal preparation, doing housework, and transporting CRs (27). This 2:1 ratio may reflect caregiving circumstance — if a CR needed assistance with multiple ADLs, which are often physical in nature, it might necessitate a higher level of care and prompt the CR's transition from informal to formal care — thus, any caregiver surveyed would be likely perform a low number of ADLs. There was no significant difference in number of ADLs performed by OACs versus younger caregivers, which is perhaps unexpected as younger caregivers would be presumed to be more able-bodied, and thus, more able to handle the physical demands of ADLs.

A minority (35%) of OACs were employed while caregiving in 1997 and that declined to 22% by 2019. People ≥ 64 years old in the U.S. are more likely to be retired, and older adults who are still employed may be less likely to take on caregiving responsibilities. A Taiwanese study found OACs self-reported better health if they were unemployed (19). Future research could clarify why fewer OACs are working and caregiving simultaneously, and any related benefits or consequences of such.

The majority of OACs in 2019, unlike their younger counterparts, indicated not needing more help to address their stress. Half of OACs felt they chose to become a caregiver while younger caregivers felt they had less choice. Caregivers also significantly differed by age group in having plans in place for their future health care with OACs more likely to have them. One U.S. study observed >30% of OACs received care while also providing care to others (28). This dual role may prompt OACs to plan for their own future health care needs.

No significant difference was found in self-reported health status and in caregiving's impact on health status between OACs and younger caregivers negating

the hypothesis. Interestingly, no difference was found in hours spent caregiving per week, with 34.5% of OACs versus 33.2% of caregivers under 64 years spending more than 20 hours a week caregiving, which suggests that caregivers in their 70s and 80s spend equal time per week caregiving as someone half their age.

Multiple studies found that constraints on an OAC's time and schedule are a particular stressor contributing to caregiving burden (21, 24). Another study found that it was actually the variety in responsibilities, not solely the hours spent caregiving, that was related to increased burden (15). PCPs could attempt to mitigate these challenges by combining OAC and CR health appointments when appropriate and viewing the OAC and CR as a dyad whose care outcomes are fundamentally linked (8, 24).

Limitations

Surveys are problematic due to: 1) response biases; 2) participant fatigue; and/or 3) inconsistencies in surveys within and across years. An example of irregularity occurred in the 2009 survey, where interviewers were instructed to input caregiver sex based on the *sound* of the participant's voice and to not ask directly (25). Moreover, the only answer choices available to interviewers were "male" and "female," with no option for "other" if the interviewer was unsure.

Conclusion

The primary objective of this research is to promote visibility and advocacy for a potentially vulnerable subgroup of caregivers in the U.S. There is an increasing percentage of caregivers who fall within the older adult age group (≥ 64 years old); and this group has become increasingly diverse in terms of sex, race, income and education. The role of OAC is becoming an increasingly new and shared experience among a more varied group of individuals and may represent an upcoming cultural and social paradigm shift. Some OACs are doing cross-generational caregiving and have multiple CRs which are likely to present with unique challenges. Lastly, significant differences exist in caregiver experience when investigating by age. One clinical recommendation is to screen all primary care patients ≥ 64 years old to determine if a patient identifies as an OAC or performs common OAC responsibilities. Earlier detection of caregiving status could lead to earlier interventions such as connecting OACs with social workers, offering periods of respite, and prioritizing self-care. Continued research assessing the unique needs of American OACs has the potential to positively impact OACs and their CRs.

Disclosures

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References

1. Medina L, Sabo S, Vespa J. Living Longer: Historical and Projected Life Expectancy in the United States, 1960 to 2060. 2020.
2. Vespa J, Medina L, Armstrong DM. Demographic Turning Points for the United States: Population Projections for 2020 to 2060. 2018, Rev 2020.
3. Goldstein JR, Lee RD. Demographic perspectives on the mortality of COVID-19 and other epidemics. *Proceedings of the National Academy of Sciences*. 2020;117(36):22035-41.
4. Center GWPS. Projected Future Need for Geriatricians. New York, NY: The American Geriatrics Society; 2017 February 2017.
5. Kozikowski A, Honda T, Segal-Gidan F, Hooker RS. Physician assistants in geriatric medical care. *BMC Geriatr*. 2020;20(1):449.
6. Smiley RA, Lauer P, Bienemy C, Berg JG, Shireman E, Reneau KA, et al. The 2017 National Nursing Workforce Survey. *J Nurs Regul*. 2018;9(3):S4-S88.
7. Rowe JW. The US eldercare workforce is falling further behind. *Nat Aging*. 2021;1(4):327-9.
8. Rose MS, Noelker LS, Kagan J. Improving policies for caregiver respite services. *Gerontologist*. 2015;55(2):302-8.
9. Boyd CM, Ritchie CS, Tipton EF, Studenski SA, Wieland D. From Bedside to Bench: summary from the American Geriatrics Society/National Institute on Aging Research Conference on Comorbidity and Multiple Morbidity in Older Adults. *Aging Clin Exp Res*. 2008;20(3):181-8.
10. He W, Larsen L. Older Americans with a disability, 2008-2012. American Community Survey Reports. Washington, DC; 2014.

11. Families Caring for an Aging America. In: Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC)2016.
12. Mukamel DB, Saliba D, Ladd H, Konetzka RT. Association of Staffing Instability With Quality of Nursing Home Care. *JAMA Network Open*. 2023;6(1):e2250389-e.
13. Taylor MG, Quesnel-Vallee A. The Structural Burden of Caregiving: Shared Challenges in the United States and Canada. *Gerontologist*. 2017;57(1):19-25.
14. Kuharic M, Mulhern B, Sharp LK, Turpin RS, Pickard AS. Comparison of the EQ-HWB and EQ-HWB-S With Other Preference-Based Measures Among United States Informal Caregivers. *Value Health*. 2024;27(7):967-77.
15. Riffin C, Van Ness PH, Wolff JL, Fried T. Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers. *J Am Geriatr Soc*. 2019;67(2):277-83.
16. Sabatini S, Turner SG, Morris RG, Opdebeeck C, Thom JM, Hunt A, et al. Correlates of felt age in caregivers of people with dementia: findings from the IDEAL study. *Front Psychol*. 2023;14:1287842.
17. Lowers J, Brus K, Smith C, Kavalieratos D, Hepburn K, Perkins MM. "How do You Take that Much Time for One Person's Life?" Experiences of Dementia Caregivers Who are Not Immediate Family. *J Appl Gerontol*. 2025;44(1):166-75.
18. Bom J, Bakx P, Schut F, van Doorslaer E. The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *Gerontologist*. 2019;59(5):e629-e42.
19. Chen MC, Kao CW, Chiu YL, Lin TY, Tsai YT, Jian YZ, et al. Effects of home-based long-term care services on caregiver health according to age. *Health Qual Life Outcomes*. 2017;15(1):208.
20. Tsai CF, Hwang WS, Lee JJ, Wang WF, Huang LC, Huang LK, et al. Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatr*. 2021;21(1):59.
21. Spatuzzi R, Giulietti MV, Romito F, Reggiardo G, Genovese C, Passarella M, et al. Becoming an older caregiver: A study of gender differences in family caregiving at the end of life. *Palliat Support Care*. 2022;20(1):38-44.
22. Fagerstrom C, Elmstahl S, Wranker LS. Analyzing the situation of older family caregivers with a focus on health-related quality of life and pain: a cross-sectional cohort study. *Health Qual Life Outcomes*. 2020;18(1):79.
23. Wranker LS, Elmstahl S, Cecilia F. The Health of Older Family Caregivers - A 6-Year Follow-up. *J Gerontol Soc Work*. 2021;64(2):190-207.
24. Sabo K, Chin E. Self-care needs and practices for the older adult caregiver: An integrative review. *Geriatr Nurs*. 2021;42(2):570-81.
25. Caregiving in the U.S. 2009, 2015, 2020 - Public Use Data Files. In: (NAC) TNAfC, editor. Caregiving: The National Alliance for Caregiving and the AARP Public Institute.
26. Shaffer KM, Nightingale CL. Comparison of Healthcare Utilization Between Informal Caregivers and Non-Caregivers: An Analysis of the Health Information National Trends Survey. *J Aging Health*. 2020;32(5-6):453-61.
27. Caregiving in the U.S. 2009, 2015, 2020 - Public Use Data Files: The National Alliance for Caregiving and the AARP Public Institute; [Available from: https://www.caregiving.org/research/open-data/].
28. Semere W, Yank V, Lisha NE, Lindquist LA, Huang AJ. Older adults with overlapping caregiving responsibilities and care needs in a U.S. national community-based sample. *J Am Geriatr Soc*. 2024;72(6):1824-30.