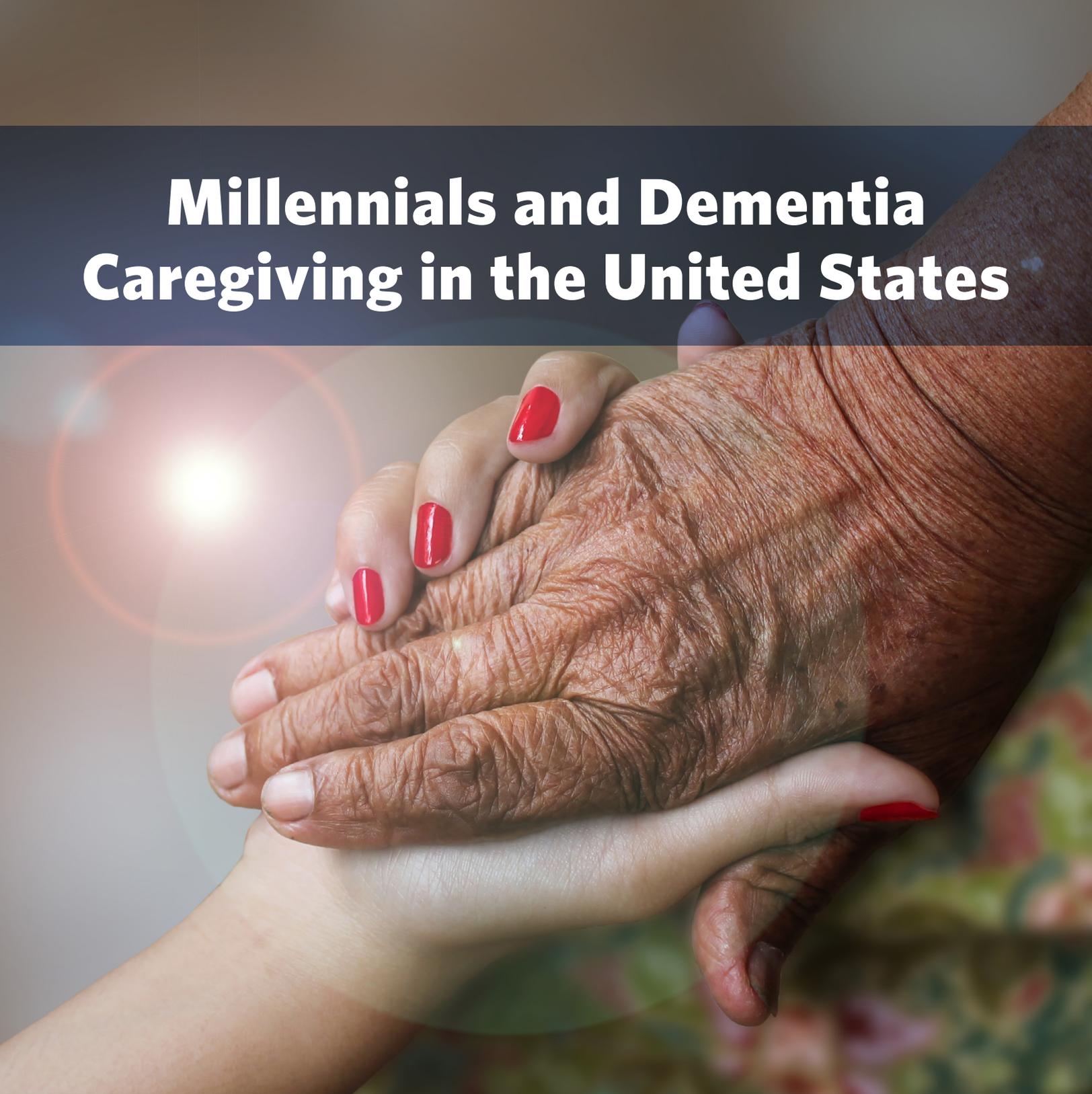


Millennials and Dementia Caregiving in the United States



CO-AUTHORS

William A. Vega, PhD, Provost Professor and Executive Director, USC Edward R. Roybal Institute on Aging

María P. Aranda, PhD, Associate Professor and Interim Executive Director, USC Edward R. Roybal Institute on Aging

Francisca S. Rodriguez, PhD, Postdoctoral Scholar, USC Edward R. Roybal Institute on Aging

Executive Summary

This issue brief explores millennial caregiving in the United States with the goal of enhancing our understanding of the experiences and challenges of young adults providing care for a family member or friend living with Alzheimer's disease or other dementias.

Alzheimer's is the most common form of dementia. Like other dementias, it is characterized by a profound deterioration in memory, language and communication abilities, problem-solving capabilities, and other aspects of cognition that affect a person's ability to perform everyday activities. Research suggests that Alzheimer's may be the third-leading cause of death among older adults.¹

To understand the challenges that millennial family caregivers face when managing Alzheimer's and other dementias, this issue brief analyzes data from the nationally representative study, *Caregiving in the U.S. 2015* conducted by the National Alliance for Caregiving and AARP. The study provides information about the characteristics of millennial caregivers caring for someone with Alzheimer's disease or other dementias, examining the caregiving activities they perform, how much burden they experience through caregiving, and how their caregiving activities interfere with their work. With the prevalence of Alzheimer's disease and dementia expected to reach nearly 16 million by 2050, more millennials and young Americans will face caregiving responsibilities in the future.² This issue brief is critical for framing policy and programming solutions to support this growing segment of the caregiver community.

Key Findings

- **Generational Status.** About one in six millennial caregivers cares for someone with dementia.
- **Gender.** More female (53%) than male (47%) millennials provided care for someone living with Alzheimer's disease or other dementia; however, there was closer gender role parity among millennials than in older segments of the caregiver population.³
- **Sole caregiver.** Roughly 42% of millennial dementia caregivers were sole caregivers and the overwhelming majority (79%) reported that accessing affordable outside help was very difficult. Millennial caregivers caring for someone living with dementia provided care for longer periods of time than non-dementia caregivers.
- **Travel & Transportation.** Most millennial dementia caregivers (84%) did not live in the same household with their care recipient/partner, and 16% had to travel more than an hour to provide care.
- **Caregiving activities.** The most common caregiving activities for millennial dementia caregivers included helping with transportation (79%), grocery shopping/shopping for other items (76%), and communicating with health care professionals (70%).
- **Emotional distress.** Millennial dementia caregivers felt emotional distress (79%) was a major caregiving burden and wanted more help to deal with this hardship.
- **Interference with work.** About one out of two millennial dementia caregivers stated that caregiving interfered with work, and 33% reported severe interference with work (e.g., cutting back hours, losing job benefits, being fired). Even though 60% of millennial dementia caregivers were offered a flexible work schedule by their employer, other types of benefits that could better facilitate caregiving coordination (e.g., working from home, paid leave, counseling) were not usually offered.

Introduction

Caregiving is a fundamental social responsibility with both rewards and challenges. This is especially true for those that provide dementia care, who must confront the dramatic decline in daily functioning of their care partners. Data shows that the typical caregiver is someone who is a close family member, usually a spouse or middle-aged adult child, a paid paraprofessional or home health worker. Caregivers are usually women, and the role is complex because it involves addressing a wide spectrum of instrumental and emotional support needs.⁴ It requires time availability, patience, endurance, initiative, specialized knowledge, and limitless energy.

“One of the reasons why I’m so vocal about my dad’s disease is because I hope that no one else my age, 20 or 30 years from now, has to take care of their dad beginning at 20 years old.” Lisette, Alzheimer’s caregiver, 26.

Research suggests that the desire to fulfill this responsibility can be motivated by love, familial expectations, and cultural beliefs.^{5,6} This is far from easy, especially when the caregiver must endure years of deteriorating health and functioning of the care partner and possibly their own declining health. Care providers may also confront resistance from their care partners frustrated by their loss of control and from family members about the quality and distribution of effort and resources. As the prevalence of dementia continues to grow in an aging America, and with increasingly earlier identification of persons with dementia, our youngest adults are emerging as a significant caregiving resource.

Using data from the nationally representative caregiver study, *Caregiving in the U.S. 2015*, we examined the sociodemographic profiles, caregiving context, and impact on the work and career of millennials who provided dementia care with selected comparisons to millennials caring with someone with other conditions. For the purpose of this issue brief, millennials are defined as the generation of young adults who were born from 1980 to 1998. Millennial caregivers are defined as persons between the ages of 18 and 34 years at the time of initial data collection who provide unpaid care to a relative or friend by helping with personal needs or household chores.⁷

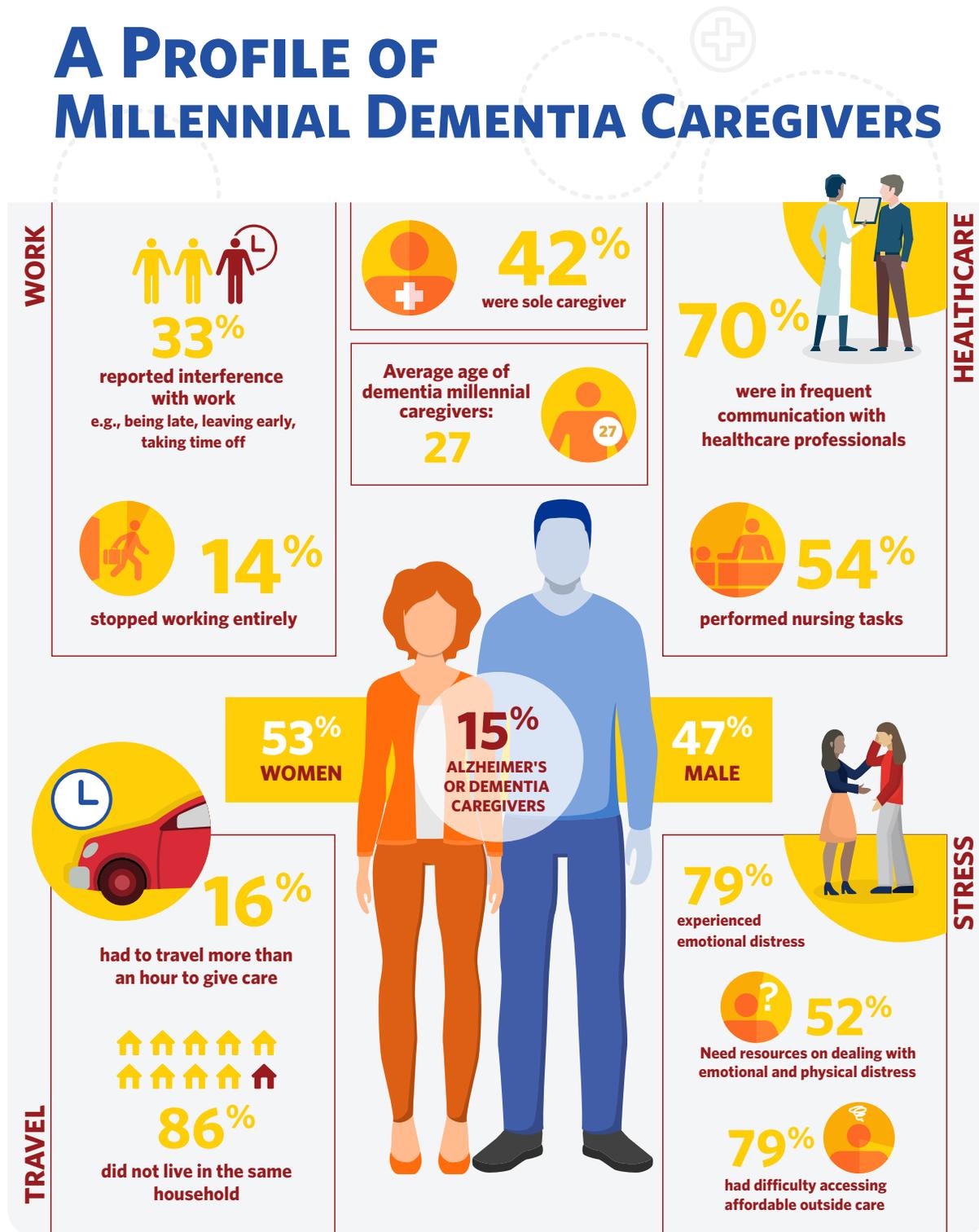
Overall, millennial caregivers accounted for almost one out of four caregivers for those with any infirmity (24%) and one in six (15%) of all millennial caregivers assisted someone living with Alzheimer’s or other dementia.



A Profile of Millennial Dementia Caregivers

Figure 1 below provides a snapshot of millennial dementia caregivers, including personal characteristics, level of demand in time and resources, potential role conflicts with daily activities, instrumental caregiving functions, and indicators of personal stress. A summary listing of this descriptive information is provided below.

FIGURE 1

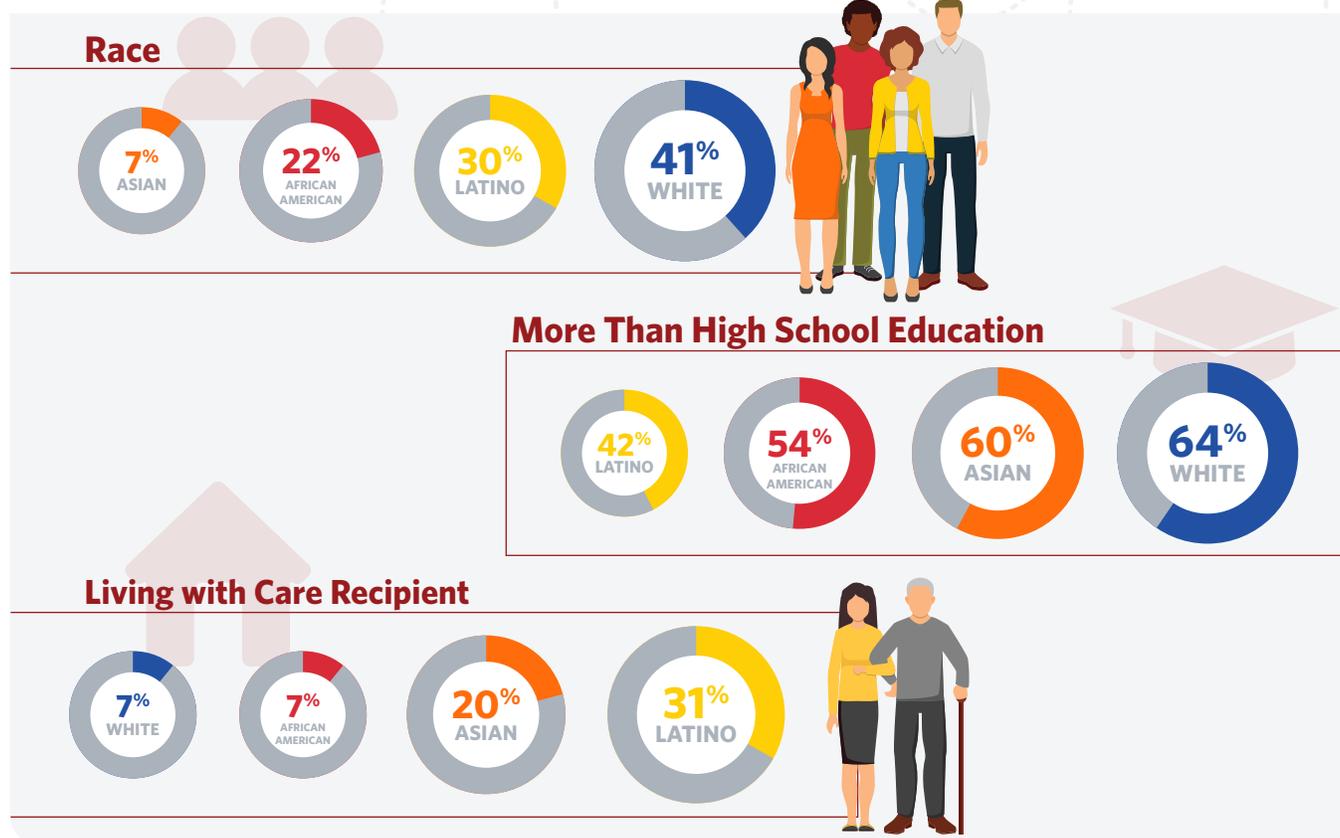


Overall, 66% of millennial caregivers provided six months to four years of caregiving. The average length at the time the data was collected was four years, while it was three years for other conditions. About half of the millennial dementia caregivers (48%) visited their care partner more than once a week. The average age of the dementia care partner was 70 years old, while other care partners were 58 years old. The average age of millennial caregivers was 27 years, and men (47%) and women (53%) were almost equally likely to be providing care, which is striking because women are much more likely to be caregivers in middle age and beyond. This finding is important because caregiving responsibilities can hinder millennials' career development and ability to establish a foundation for their peak earning years. Almost half of millennial caregivers were sole care providers, 54% performed nursing tasks, and 70% of them were frequently engaged in communicating with health care professionals.

Figure 2 presents information on the education level, ethnic breakdown and residential situation of millennial dementia caregivers. In general, 45% had a high school degree, Whites and Asians had higher high school completion rates, closely followed by African Americans, and Latinos had the lowest. Latino and Asian caregivers were the most likely to reside with a dependent care partner, while Whites and African Americans were the least likely to do so.

FIGURE 2

ETHNIC/RACIAL DIFFERENCES IN MILLENNIAL DEMENTIA CAREGIVERS



Transportation Impact

Driving time is a critical factor in facilitating or impeding the caregiving process. This is particularly true given the inherent strain of home and work obligations and the cost that driving time imposes, as well as the additional transportation requirements of dependent partners requiring access to food, social programs, family visits, and medical and pharmacy services. About 55% of the millennial caregivers were driving up to 20 minutes simply to reach the partner's residence, 20% were driving 20 to 60 minutes, and 10% reported a travel time of two hours or greater. The impact of the transportation burden on caregiving could be expected to intensify as the functional status of the care partner declines.

What caregiving activities do millennial caregivers perform?

The role of caregiver is extremely varied and demanding, involving multiple practical activities, and navigating and facilitating engagement with the world beyond the household. This includes financial and medical obligations as well as household maintenance. The challenges are amplified when addressing the needs of people with dementia who will eventually become completely dependent on others, suffer from confusion, and can potentially injure themselves.

Managing Finances

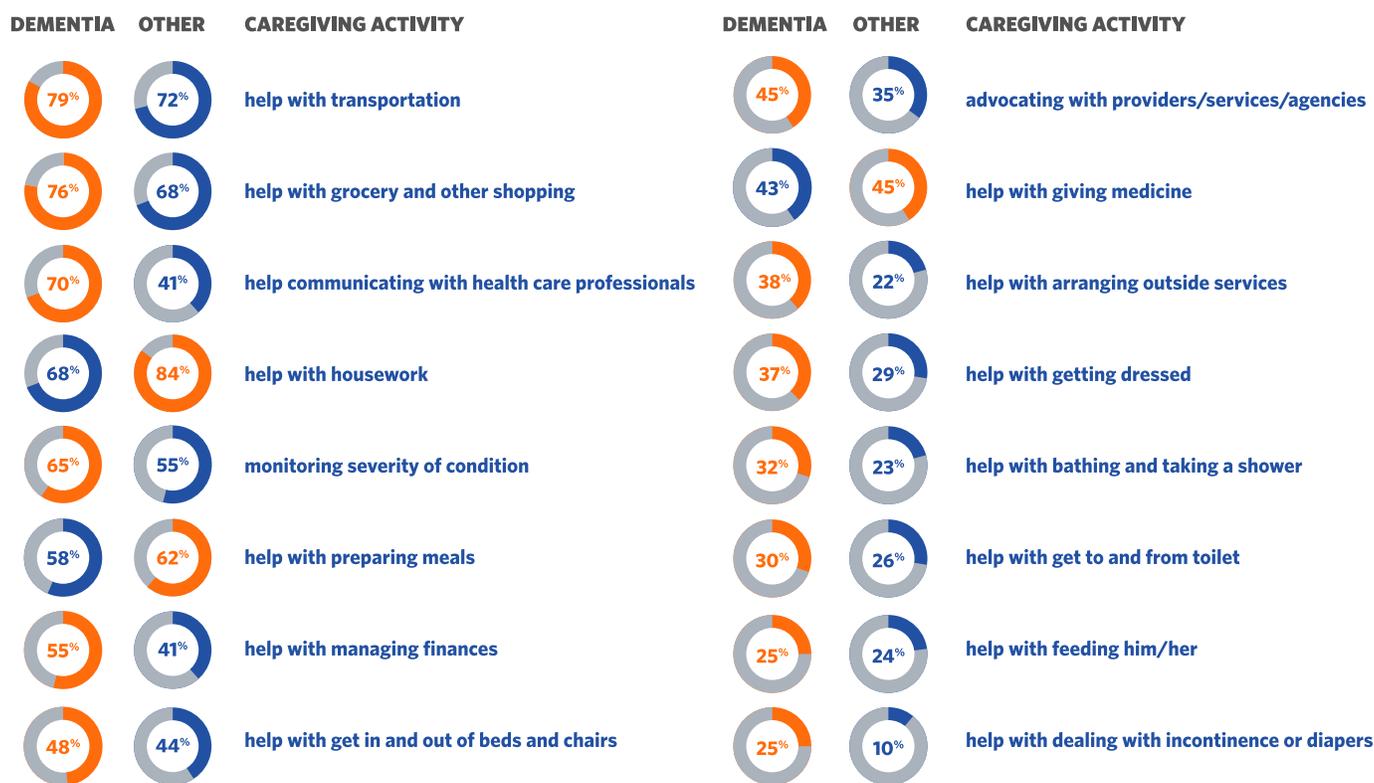
Another area of growing concern is the need for assistance in managing finances. This is a controversial area for many reasons, and too often a source of stress and strain for families managing dementia care. The potential for problems depends on the level of control that must be exercised by caregivers, especially in resource scarce situations. The potential problems are many, ranging from basic competence in taking care of the personal and household needs in a timely fashion, and can extend much further into issues related to access to and expenditure of financial assets that bring a host of serious implications for the person living with dementia and the entire family. The extent to which all millennial caregivers are actually taking control of financial assets or can competently provide stewardship of financial obligations remains unknown, yet the high percentage of millennials (52%) that are sole caregiver providers suggests that this is an area that requires greater scrutiny as a public policy and personal finance issue for policymakers and the business community.

Medical Assistance

Figure 3 compares percentages of dementia and non-dementia millennial caregivers involved with a range of activities. In general, dementia care partners required more intensive support across the spectrum of care activities than non-dementia partners. Dementia care involves managing multiple activities of daily living – such as assisting the care partner with bathing and dressing when this is no longer possible on his or her own. A total of 74% assisted with two or more instrumental activities (IADLs) – such as preparing a meal or managing finances (about the same as non-millennial caregivers and caregivers of dementia patients). Millennial caregivers of individuals living with dementia were frequently engaged in communicating with health care professionals far more than non-dementia patients (70% vs. 41%). As individuals living with dementia experience progressive cognitive decline, they are often not able to advocate for their own health needs and caregivers play an essential role in medical care. This is an especially problematic area for millennial caregivers with limited or no experience with geriatric health care, medication management, or navigating the health care system. A related challenge for dementia caregivers is performing medical tasks for care partners who may have a limited ability to articulate needs, or adverse effects of drugs and other forms of physical discomfort. The growing number of non-English language dominant dementia patients underscores the need for effective translation in all aspects of medical care and patient management, which often falls on millennial caregivers with varied levels of linguistic competence to provide regular translation services.⁸ This is a key issue for medical and social care providers as they work to improve the quality of care available to their patients.



FIGURE 3 - CAREGIVING ACTIVITIES BY MILLENNIAL CAREGIVERS



The Impact of Dementia Care on Millennials

The physical and emotional strain that caregiving places on care providers is well documented and this trend holds with millennial caregivers. Approximately 18% of millennial dementia caregivers reported a worsening of their own health, suggesting that even among very young adults, health can be negatively affected by the strains of caregiving. Further, one out of two or 52% of millennial dementia caregivers expressed the need for information and support to manage their emotional and physical distress.

“I can handle the logistics, the doctor’s appointments, and all of that stuff. It’s the social and emotional support that’s the hardest for me.”

Kamaria, Alzheimer’s caregiver, 32.

What do millennial dementia caregivers need help with?

- Overall, 42% reported being the sole caregiver.
- 58% received unpaid assistance from relatives, friends, and neighbors.
- 79% reported it is often difficult to get outside care services.
- 52% expressed the need for more information on how to deal with their emotional and physical distress.
- 23% want information on managing challenging behaviors such as wandering.

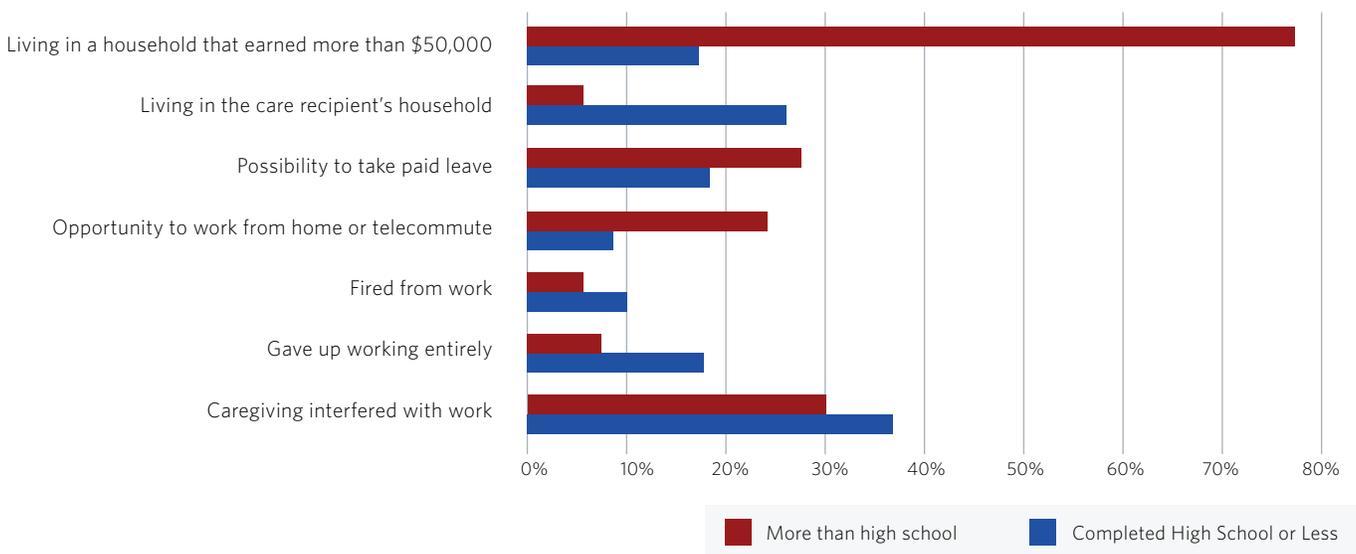
The role of caregiving has a direct effect on the millennial dementia caregivers' work-life balance with 14% reporting losing job benefits or having to stop working. As expected, those millennials who only completed high school or less than high school reported more hardships in their personal living circumstances and careers.

“When I was ready to resume working, job-hunting was difficult. I couldn't help but feel ashamed of the gap on my resume, despite the fact that I was grateful to have spent that time with my dad. No one should have to choose between earning money and caring for a sick loved one.” Caitlin, Alzheimer's caregiver, 33.

Education as a Determinant of Millennial Caregiver Quality of Life

Figure 4 compares those with and without high school completion on several key lifestyle aspects associated with stress in caregiving.

FIGURE 4 - EDUCATIONAL ATTAINMENT DIFFERENCES



Millennial dementia caregivers with low levels of education (completed high school or less) were more likely to live in a low-income household and/or the care partner's household and to experience negative impacts on their employment due to caregiving. They were less likely to telecommute. This data underscores the lack of alternatives to home assistance for dementia care partners, and suggests a need to support millennial caregivers with programs and financial assistance at the federal, state, and local levels. Without this type of support, we risk leveling an unfair penalty on the economic mobility of the most financially disadvantaged millennial caregivers. Millennials are in a critical period of transition as they develop families, careers, and wealth.

Recommendations

The issue brief highlights some of the challenges faced by young adults who act as caregivers for individuals living with Alzheimer's or other dementia on a regular basis. The following recommendations address these issues:

Improved Access to Transportation . One of the major issues millennial dementia caregivers must deal with is transportation, including transportation to where care partners live and transportation of the care partners themselves. It is critical to develop transportation solutions that work for caregivers and their care partners. For instance, in-home medical services for the patient and telemedicine options could be helpful in alleviating the hardship that travel represents for many millennial caregivers. Additionally, it is critical to consider how ride-sharing providers like Lyft and Uber can play a role in meeting the demands of millennial caregivers. Partnerships between these companies and medical systems have shown promise in connecting low-income and older patients to essential services. Another option includes the piloting of autonomous cars to connect caregivers and care partners to medical and social services. Finally, as it would also be helpful for caregivers to live closer to their care partners, city planners should consider the specific needs of caregivers and older residents as they upgrade new communities and build new ones.

Increased Access to Affordable and Tailored Services and Information. It is critical to improve access to Alzheimer's and dementia caregiving resources for millennials providing this highly specialized care, including tailored training and support groups that take into account the cultural and age-specific needs of millennials. As one in two millennial caregivers expressed a need for more information on how to deal with their emotional and physical distress, communities and health systems must develop psychosocial and emotional support interventions that meet these needs. Further, researchers should examine the unique impacts of caregiving on younger care providers to inform the development of effective interventions and community supports.

Communication with health care providers. Advocating, navigating, and communicating with medical professionals is a central caregiving activity, especially for those who provide care for individuals living with Alzheimer's or dementia given the impact of these diseases on cognition and decision making. Millennials providing dementia care were more likely to communicate with health professionals on behalf of care partners than millennials providing care for individuals with other conditions. However, these caregivers have limited knowledge about disease progression and effective treatment plans. Medical professionals, on the other hand, do not have the opportunity to monitor disease progression with the same level of intensity as a caregiver. More effective collaboration between both parties is necessary to ensure quality care. Solutions may include the development of online communication platforms, technologies, and tools that help young caregivers track symptoms, medications, and execute care strategies for their care partners.

Flexible work arrangements. Navigating and balancing work and caregiving responsibilities can be difficult for millennials. While paid leave options offer critical assistance in some states, they are largely unavailable to many employees.⁹ However, flexible work arrangements may significantly ease the burden of caregiving. Flexible work hours and telecommuting are benefits that employers can offer can make a major difference for someone with caregiving responsibilities. Unfortunately, even these opportunities may not be offered to caregivers at the lowest income levels. Along with advocating with employers to make flexible work arrangements more widely available, more research is needed to explore the feasibility and obstacles for offering these beneficial arrangements to employees at the beginning of their careers.

**“I was only at the University of Virginia for a few months when I found out my dad had Alzheimer's disease. The first few months were very tough. My focus shifted from graduating to ‘how am I going to support my family now that my dad is sick?’
*Lisette, Alzheimer's caregiver, 26.***

Methods

To understand the challenges of millennial caregivers, we analyzed data from the nationally representative study *Caregiving in the U.S. 2015*,¹⁰ which was conducted by the National Alliance for Caregiving and AARP to gather information on family caregiving in the United States.

A millennial caregiver was between 18 and 34 years old at the time of the interview, in accordance with the definition used by the U.S. Census Bureau.¹¹ A total of 235 caregivers met that criteria and were considered millennial caregivers. We calculated the frequency and distribution of individual characteristics, caregiving activities, and burden due to caregiving by estimating proportions with confidence intervals using logit transform adjusted for sampling weights. The sampling weights were provided by the study and represent the distribution of caregivers in the population with respect to age, gender, and race/ethnicity (2014 U.S. Census). Percentages expressed in this issue brief were corrected for sampling weights.

Data analyses focused on care partners with “dementia.” In the survey data, Alzheimer’s disease, related dementias, and other forms of mental confusion all fall under the same category of conditions in response to the question: “Does/Did your [relation] suffer from Alzheimer’s or other mental confusion?” Not all care partners may have dementia. Self-reported responses are also based on the subjective perceptions of caregivers.

Sampling-weight adjusted proportions and means were calculated by standardized survey estimation in Stata 14. Differences between (i) millennial caregivers and non-millennial caregivers, (ii) millennials providing care for patients with dementia and millennials providing care for patients with other conditions, and (iii) millennials with low education (having completed high school or less) and high education (more than high school) were computed using the Adjusted Wald Test. Results were reported even if not statistically significant. In addition, we compared differences between.



Limitations

Because the issue brief is based on answers provided in an interview, the statistics derived in this issue brief are based on subjective perceptions only. There was no possibility to validate the answers provided by the participants. Subjective variations in intensity may not necessarily reflect the same level of effort. Further, subjective perceptions may be culturally influenced. It was not possible to take into account those cultural influences when estimating ethnic disparities in the answers. The frequency of caregiving activities can reflect the physical capacity of the patient as well as what the caregiver feels responsible for.

Moreover, as the sample size for analysis was rather small, the analyses may overestimate group differences or be subject to Type I error (i.e., not finding a significant effect even though it is true). We avoided any analysis with a subgroup $n < 5$. However, variance for some variables may be so strong that the sample of this study did not capture it well enough. This may be particularly true for the ethnic and racial disparities and differences between caregivers of dementia patients and caregivers of patients with other conditions.

Acknowledgments

This publication marks another important collaboration of the USC Edward R. Roybal Institute on Aging, the USC Suzanne Dworak-Peck School of Social Work, and UsAgainstAlzheimer's to more fully understand and recognize the challenges and contributions of the many millennial caregivers who care for loved ones with Alzheimer's disease and other dementias across in the United States.

The development of this issue brief would not have been possible without the support of UsAgainstAlzheimer's. We thank George Vradenburg for his continued commitment to building an inclusive Alzheimer's disease movement through investments in awareness, research, and advocacy.

Recommended Citation: Vega, W. A., Aranda, M. P., & Rodriguez, F. (2017). Millennials and Dementia Caregiving in the United States. USC Edward R. Roybal Institute on Aging and UsAgainstAlzheimer's.

Design by Creative Core, LLC.

Reviewers

Jason Resendez, Sr. Advisor for Youth Outreach, UsAgainstAlzheimer's
Iris Aguilar, Assistant Director, USC Edward R. Roybal Institute on Aging
Vincent Lim, Writer, USC Edward R. Roybal Institute on Aging
Katherine Rose, Director of National Relations, The Youth Movement Against Alzheimer's

For a list of caregiving resources, please visit: <https://roybal.usc.edu/genYcare>

About the USC Edward R. Roybal Institute on Aging

The [USC Edward R. Roybal Institute on Aging](#) builds upon the USC Suzanne Dworak-Peck School of Social Work's longstanding tradition of conducting socially relevant research, innovating educational practices, influencing policy making, fostering community-university partnerships and sharing best practices with direct service providers.

The USC Roybal Institute maintains a strong interdisciplinary focus, with collaborations among faculty and professionals in such fields as social work, gerontology, psychology, preventive medicine, family medicine, psychiatry, oncology, American studies and ethnicity, and public policy.

Its mission is to advance research whose goal is to enhance optimal aging for persons in minority and low-income communities.

About UsAgainstAlzheimer's and The Youth Against Alzheimer's Coalition

[UsAgainstAlzheimer's](#) is an innovative non-profit organization demanding—and delivering—a solution to Alzheimer's. Driven by the suffering of millions of families, UsAgainstAlzheimer's presses for greater urgency from government, industry and the scientific community in the quest for an Alzheimer's cure—accomplishing this through effective leadership, collaborative advocacy, and strategic investments.

Co-convened by the YouthAgainstAlzheimer's Network - a network of UsAgainstAlzheimer's - and The Youth Movement Against Alzheimer's (YMAA), the Youth Against Alzheimer's Coalition (YAAC) positions Alzheimer's as an urgent economic and public health issue impacting families across generations, mobilizing young people and youth-serving organizations through storytelling, advocacy, and coalition building.



References

1. James, B. D. et al. "Contribution of Alzheimer Disease to Mortality in the United States." *Neurology* 82.12 (2014): 1045-1050. PMC. Web. 10 Aug. 2016.
2. Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. *Alzheimers Dement.* 2017;13:325-373.
3. Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. *Alzheimers Dement.* 2017;13:325-373.
4. Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. *Alzheimers Dement.* 2017;13:325-373.
5. Aranda, M. P., & Knight, B. G. 1997. The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: A Sociocultural Review and Analysis. *The Gerontologist* 37(3):342-54.
6. Knight, B. G., & Sayegh, P. 2010. Cultural values and caregiving: the updated sociocultural stress and coping model. *J Gerontol B Psychol Sci Soc Sci* 65B(1): 5-13.
7. Vespa, J. 2017. The Changing Economics and Demographics of Young Adulthood: 1975-2016. Washington, DC: U.S. Department of Commerce, United States Census Bureau.
8. National Alliance for Caregiving; AARP Public Policy. 2015. Caregiving in the U.S. 2015. Bethesda, MD & Washington, DC: AARP Public Policy Institute.
9. Klerman, J. A., Daley, K., & Pozniak, A. 2012. Family and Medical Leave in 2012: Technical Report (Cambridge, MA: Abt Associates), available at <https://www.dol.gov/asp/evaluation/fmla/FMLA-2012-Technical-Report.pdf>.
10. National Alliance for Caregiving; AARP Public Policy. 2015. Caregiving in the U.S. 2015. Bethesda, MD & Washington, DC: AARP Public Policy Institute.
11. Vespa, J. 2017. The Changing Economics and Demographics of Young Adulthood: 1975-2016. Washington, DC: U.S. Department of Commerce, United States Census Bureau.

